

2nd European Polio Conference: 'Post-Polio Syndrome Conference. A condition without boundaries' *Amsterdam, The Netherlands June 25–27, 2014*



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Kristian Borg, MD, SE (Chair), Frans Nollet, MD (Co-chair), NL, Jan Lexell, MD, SE, Lise Kay, MD, DK, Marianne Visser, MD, NL, Antonio Toniolo, MD, IT, Laura Bertolasi, MD, IT, Arzu On, MD, TR, Alain Yelnik, MD, FR, Merete Bertelsen, PT, DK, Els Symons, NL, John McFarlane, IR, Jozef Opara, MD, PL, Johan Klavik Stanghelle, MD, NO, Enric Portell, MD, ES, Helena Burger, MD, SI, Gunilla Östlund, MD, SE, Anita Beelen, MD, NL, Alex Ruetz, MD, DE.

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Greetings from the President

This special issue of *Journal of Rehabilitation Medicine* contains all abstracts of the 2nd European Polio Conference: ‘Post-Polio Syndrome, A Condition Without Boundaries’, which was held from 25 to 27 June 2014 in Amsterdam, the Netherlands.

After the successful first European Polio Conference ‘Post-Polio Syndrome, A Challenge Of Today’ in September 2011, in Copenhagen, the scope of the present Conference was broadened to cover all health care issues of poliomyelitis: from the global health perspective to successfully complete the endgame of the eradication of the polio virus, to the needs and treatment of polio survivors from young to old in low- and high-income countries.

The Conference theme refers to the fact that many of the estimated 20 million people around the world, who are disabled by polio, have or may develop post-polio syndrome, that is characterized by late, progressive decline in muscle function, resulting in increasing disability, later on in life.

Across the world, the health problems of polio differ, mainly depending on the moment in time that polio vaccination was successfully implemented in the health care system and countries became free of polio. In developed countries polio vaccination was introduced in the late fifties of the previous century. In these countries most polio survivors are in their late fifties or older and many suffer from post-polio syndrome. In countries where polio epidemics lasted longer, and in some where polio is still endemic, there are many young polio survivors who require treatment for their polio deformities to improve their physical functioning and societal participation. In many of these countries, the numbers of polio survivors have decreased rapidly over the last decades due to the increasing success of the Global Polio Eradication Initiative. Many of them will be confronted with post-polio syndrome in the coming years.

Not only the polio virus crosses borders between countries, also the polio survivors do. In Europe there are many young polio survivors who contracted polio outside Europe in their country of birth. But the knowledge of health care providers differs between countries. In countries where new polio cases disappeared decades ago, there is knowledge of how to treat post-polio syndrome, but the medical knowledge on how to treat severe polio deformities at younger age is limited. The opposite is true for countries where new cases of polio remained to occur until recent days or still occur.

Although new polio cases are strongly reduced in number, and hopefully will cease to occur in the near future, there are many polio survivors alive today who do require good medical care and rehabilitation for decades to come. In this 2nd European Polio Conference health care workers and researchers of many disciplines involved in polio prevention and treatment, and polio survivors living in Europe and around the world, came together to ‘cross boundaries’ by interacting and sharing knowledge, with a shared aim, which was to improve care provision and to promote research in this field.

Frans Nollet, MD, PhD

Chair 2nd European Polio Conference

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PROGRAMME

WEDNESDAY JUNE 25, 2014

09.00–10.30	Plenary Opening Conference	
09.00–09.15	Welcome, <i>Frans Nollet (NL)</i>	
09.15–09.30	Dutch Patients' Organisation for Muscle Diseases, <i>Dick Van Dijk (NL)</i>	
09.30–09.50	Polio Eradication Initiative, <i>Jan Lukas Ket (NL)</i>	PL1
09.50–10.10	Polio Eradication Progress, <i>Hamid Jafari (CH)</i>	PL2
10.10–10.30	Paralysed with Fear, <i>Gareth Williams (UK)</i>	PL3
10.30–11.00	Coffee Break	
11.00–12.00	Plenary Session – Congress Themes	
11.00–11.15	Pathophysiology of Post-Polio Syndrome – New Avenues for Treatment? <i>Frans Nollet (NL)</i>	PL4
11.15–11.30	Treatment of Young Polio Survivors in and Outside Europe, <i>Kristian Borg (SE)</i>	PL5
11.30–11.45	Living with Polio in Europe from a Different Cultural Background, <i>Ramneek Dev (DK)</i>	PL6
11.45–12.00	Life with Polio in Ethiopia: My Take, <i>Dagnachew Wakene (ET)</i>	PL7
12.00–13.30	Lunch – Performance/Poster Viewing	
13.30–15.00	Symposium SS1 – Polio Survivors Theme: Ventilatory Support, Speech and Swallowing Problems	
13.30–14.00	A Life of a Polio-Survivor Beginning and Ending as a Respirator-User, <i>Holger Kallehaug (DK)</i>	SL1
14.00–14.30	Ventilatory Support in Patients with Post-Polio Syndrome, <i>Michael Gaytant (NL)</i>	SL2
14.30–15.00	Dysphagia and Dysphonia, <i>Paivi Annikki Tupala (NO)</i>	SL3
13.30–15.00	Symposium SC1 – Clinical Practice Theme: Treatment of Young Polio Survivors in and Outside Europe	
13.30–14.00	Treatment of Young Immigrants in Europe, <i>Kristian Borg (SE)</i>	SL4
14.00–14.30	Treatment of Young Polio Survivors in Turkey, <i>Arzu On (TR)</i>	SL5
14.30–15.00	Corrective Surgery from A Patient Centered Perspective for Polio Residuals in India, <i>Mathew Varghese (IN)</i>	SL6
13.30–15.00	Symposium SR1 – Research Theme: Eradication of Polio and Virus Persistence	
13.30–14.00	Polio Surveillance: Basis for Successful Eradication, <i>Harrie Van Der Avoort (NL)</i>	SL7
14.00–14.30	Development of Inactivated Polio Vaccine Based on Attenuated Sabin Poliovirus Strains: Manufacturing, Clinical Trials and Technology Transfer, <i>Wilfried Bakker (NL)</i>	SL8
14.30–15.00	Persistence of Poliovirus Genome in Polio Survivors Diagnosed with Post-Polio Syndrome, <i>Antonio Toniolo (IT)</i>	SL9

15.00–15.30	Coffee Break	
15.30–16.30	Workshop WS1 – Polio Survivors	
	Management of Bladder and Bowel Symptoms, <i>Lise Kay (DK), Anne Marie Eriksen (DK)</i>	WS1
15.30–16.30	Workshop WS2 – Polio Survivors	
	Exoskeletons for Enhancement of Patients with Neuromuscular Deficiencies, <i>Frans Van Der Helm (NL), Just Herder (NL), Heike Vallery (NL)</i>	WS2
15.30–16.30	Workshop WS3 – Polio Survivors	
	The Caregiver and Issues in Society, <i>Jan Lexell (SE), Anja Horemans (NL), Mary Mcfarlane (IE)</i>	WS3
15.30–16.30	Guided Poster Tours PT1 – Professionals	
16.30–17.30	Free Papers Session FP1 – Professionals Clinical Studies & Research Methodology	
16.30–16.45	Blood Lipids Low in Patients with Post-Polio Syndrome, <i>Eva Melin (SE)</i>	FP1
16.45–17.00	Quantitative Muscle Ultrasound and Quadriceps Strength in Patients with Post-Polio Syndrome, <i>Alice Bickerstaffe (NL)</i>	FP2
17.00–17.15	The Neurological Fatigue Index for Post-Polio Syndrome (NFI-PP): A Patient Derived, Rasch-Standard Scale, <i>Carolyn Young (UK)</i>	FP3
17.15–17.30	Development and Validation of Neurological Coping Index – Post-Polio Syndrome (NCI-PPS), <i>Kristijonas Milnis (UK)</i>	FP4
16.30–17.30	Workshop WC1 – Clinical Practice International Exchange of Experiences between Polio Clinics	
	The Polio-Clinic, <i>Katharina Stibrant Sunnerhagen (SE)</i>	WS4
	An Interdisciplinary Modular Programme for Post-Polio Patients, <i>Axel Ruetz (DE)</i>	WS5
	Interdisciplinary Approach of Polio and Post-Polio Syndrome in a Rehabilitation Center in Catalonia (Spain), <i>Enric Portell (ES)</i>	WS6
16.30–17.30	Workshop WR1 – Research	
	Gait Studies in Poliomyelitis, <i>Isabelle Laffont (FR), Hilde Ploeger (NL), Christina Brogårdh (SE)</i>	WS7

THURSDAY JUNE 26, 2014

08.00–09.00	Workshops WP1 – Professionals	
	Clinimetrics – What Should We Measure for What Purpose? <i>Anita Beelen (NL), Jozef Opara (PL), Christina Brogårdh (SE)</i>	WS8
08.00–09.00	Workshops WP2 – Professionals	

	Exercise – From Theory to Practice, <i>WS9</i> <i>Merete Bertelsen (DK), Eric Voorn (NL), Deirdre Murray (IE)</i>	11.00–11.15	Self Management of the Late Effects of Polio – Seeking Government and Private Funding Support: The Australian Experience, <i>John Tierney (AU)</i>	<i>FP9</i>
08.00–09.00	Workshops WP3 – Professionals			
	Orthotics – Guideline-Based Prescription Practice, <i>WS10</i> <i>Merel Brehm (NL), Parwin Yari (NL), Tom Gort (NL)</i>	11.15–11.30	Painting the Same Picture Can Provide Better Clinical Outcomes, <i>Hilary Ann Boone (UK)</i>	<i>FP10</i>
09.00–10.30	Symposium SS2 – Polio Survivors			
	Theme: Aging & Comorbidity			
09.00–09.30	Aging and Muscle Function Including Sarcopenia, <i>Jan Lexell (SE)</i>	11.30–11.45	Illness Experiences of People with Post-Polio Syndrome, <i>Minne Bakker (NL)</i>	<i>FP11</i>
09.30–10.00	Osteoporosis in Polio Survivors, <i>Helena SL11</i> <i>Burger (SI)</i>	11.45–12.00	Learning from the Past: Polio Survivors Experiences Prior to the Creation of the British National Health Service, <i>Anita Atwal (UK)</i>	<i>FP12</i>
10.00–10.30	Medication for Comorbidities; Effects in Post-Polio Syndrome? <i>Lise Kay (DK)</i>	<i>12.00–13.30</i>	<i>Lunch/Poster Viewing</i>	
09.00–10.30	Symposium SC2 – Clinical Practice	13.30–15.00	Symposium SS3 – Polio Survivors	
	Theme: Best Practices for Post-Polio Syndrome: Making the Diagnosis		Theme: Symptom Management – What To Do with Pain, Fatigue, Sleep Problems?	
09.00–09.30	Diagnostic Criteria for Post-Polio Syndrome, <i>Steve Sturman (UK)</i>	13.30–14.00	Managing Pain in Polio, <i>Marguerite SL19</i> <i>Preudhomme (FR)</i>	
09.30–10.00	Differential Diagnosis of Post-Polio Syndrome and the Role of Muscle Imaging, <i>Marianne De Visser (NL)</i>	14.00–14.30	What To Do with Fatigue Problems in Post-Polio Syndrome? <i>Gunilla Östlund (SE)</i>	<i>SL20</i>
10.00–10.30	The Role of EMG Investigations in Post-Polio Syndrome, <i>Arzu On (TR)</i>	14.30–15.00	Sleep and Neuro-Muscular Disease, <i>SL21</i> <i>Hans Hamburger (NL)</i>	
09.00–10.30	Symposium SR2 – Research	13.30–15.00	Symposium SC3 – Clinical Practice	
	Theme: Post-Polio Syndrome: Psychological Interventions		Theme: Best Practices for Post-Polio Syndrome – Rehabilitation	
09.00–09.30	Resilience and Psychological Reactions in Polio Survivors, <i>Anne-Kristine SL16</i> <i>Schanke (NO)</i>	13.30–14.00	Best Rehabilitation Practices for Post-Polio Syndrome, <i>Fieke Koopman (NL)</i>	<i>SL22</i>
09.30–10.00	Cognitive Behavioral Therapy, <i>Sandra SL17</i> <i>De Moree (NL)</i>	14.00–14.30	Exercise Interventions in Post-Polio Patients, <i>Gunnar Grimby (SE)</i>	<i>SL23</i>
10.00–10.30	Hope and Well-Being of Patients with Post-Polio Syndrome: Implications for Psychotherapy, <i>Shimon Shiri (IL)</i>	14.30–15.00	Interdisciplinary Teamwork and Rehabilitation Plans, <i>Jan Lexell (SE)</i>	<i>SL24</i>
<i>10.30–11.00</i>	<i>Coffee Break</i>	13.30–15.00	Symposium SR3 – Research	
11.00–12.00	Workshop WS4 – Polio Survivors		Theme: Pathophysiology & Immunological Aspects	
	Speech & Swallowing Therapy, <i>Sandra WS11</i> <i>Offeringa (NL), Paivi Annikki Tupala (NO), Thomas Lehmann (CH)</i>	13.30–13.55	The Immunobiology of Post-Polio Syndrome, <i>Marinos Dalakas (US)</i>	<i>SL25</i>
11.00–12.00	Free Papers Session FP2	13.55–14.20	Treatment of Post-Polio Syndrome with Immunoglobulins, <i>Kristian Borg (SE)</i>	<i>SL26</i>
	– All Delegates	14.20–14.40	Loss of Motor Unit Size and Quadriceps Strength over 10 Years in Post-Polio Syndrome, <i>Alice Bickerstaffe (NL)</i>	<i>SL27</i>
	Societal Issues in (Until Recent) Endemic Countries	14.40–15.00	Brain Volume Studies in Post-Polio-myelitis Syndrome Patients, <i>Daria SL28</i> <i>Trojan (CA)</i>	
11.00–11.15	Polio & Post-Polio Syndrome Need attention Regarding Palliative Care in a Rural (Desert) Community of Pakistan, <i>Jewat Sunder (PK)</i>	<i>15.00–15.30</i>	<i>Coffee Break</i>	
11.15–11.30	Discrimination of Polio Survivors in India, <i>Krithika Murali (IN)</i>	15.30–16.30	Workshop WS5 – Polio Survivors	
11.30–11.45	Afterthought: Living with Polio in the Post-Elimination Era, <i>Mitali Thakore (USA)</i>		Coping & Psychological Issues – Old Habits Die Hard, <i>Gunilla Östlund (SE), Sandra De Moree (NL)</i>	<i>WS12</i>
11.45–12.00	The Relationship between the Polio Endemic and Extreme Poverty in the Northern Part of Nigeria, <i>Ponnle Lawson (UK)</i>	15.30–16.30	Workshop WS6 – Polio Survivors	
11.00–12.00	Free Papers Session FS1 – Polio Survivors		International Exchange of Experiences between Polio Support Groups, <i>John Mcfarlane (IE), Els Symons (NL)</i>	<i>WS13</i>
	Coping and Exchange of Experiences	15.30–16.30	Workshop WS7 – Polio Survivors	
			Nutrition for Post-Polio Syndrome, <i>Frances Quinn (UK), Coby Wijnen (NL)</i>	<i>WS14</i>
		15.30–16.30	Guided Poster Tours PT1 – Professionals	
		16.30–17.30	Free Papers Session FP3 – Professionals	
			Intervention Studies	

16.30–16.45	The Effects of a Home-Based Arm Ergometry Exercise Programme on Physical Fitness, Fatigue and Activity in Polio Survivors; a Randomised Controlled Trial, <i>Deirdre Murray (IE)</i>	FP13	09.30–10.00	Stance-Control Orthoses in Polio, <i>Frans Nollet (NL)</i>	SL33
16.45–17.00	Exercise Therapy and Cognitive Behavioural Therapy to Improve Fatigue in Post-Polio Syndrome: Preliminary Results of a Randomised Controlled Trial, <i>Fieke Koopman (NL)</i>	FP14	10.00–10.30	Orthotics in Developing Countries, <i>Raphael Amuzu Dzameshie (GH)</i>	SL34
17.00–17.15	IVIG Treatment in Post-Polio Syndrome, <i>Peter Arlien-Soborg (DK)</i>	FP15	09.00–10.30 Symposium SC5 – Clinical Practice Theme: What Can We Learn from Each Other's Practices?		
17.15–17.30	Restless Leg Syndrome in Poliomyelitis, <i>Enric Portell (SP)</i>	FP16	09.00–09.30	Post-Polio Patients in Norway; Past and Present Rehabilitation, <i>Ingebjørg Irgens (NO)</i>	SL34
16.30–17.30 Workshop WC2 – Clinical Practice	Multidisciplinary One-day Rehabilitation Team Evaluation for Post-polio Syndrome Patients, <i>Parwin Yari (NL), Anne Carien Beishuizen (NL), Dorien Toor (NL), Liesbeth Eggink (NL)</i>	WS15	09.30–10.00	What Can We learn from Each Other Practices? <i>Laura Bertolasi (IT)</i>	SL35
16.30–17.30 Workshop WR3 – Research	International Research Collaboration, <i>Kristian Borg (SE)</i>	WS16	10.00–10.30	Breaking the Silence: Coping With Polio in a Third World Country, <i>Emmanuel Piki (ZW)</i>	SL36
FRIDAY JUNE 27, 2014					
08.00–09.00 Workshop WP4 – Professionals	Physio- and Occupational Therapy Inspiration across Borders, <i>Merete Bertelsen (DK), Katja Appelin (SE)</i>	WS17	10.30–11.00	Coffee Break	
08.00–09.00 Workshop WP5 – Professionals	Deformity Correction in Post-Polio Residual Paralysis, <i>Mathew Varghese (IN), Matthias Schafroth (NL)</i>	WS18	11.00–12.00 Workshop WS8 – Polio Survivors	Wheelchairs for Polio Survivors, <i>Dorien Toor (NL), Kees Sytsma (NL)</i>	WS19
08.00–09.00 Free Papers Session FP4 – Professionals	Gait Studies & Orthotic Devices		11.00–12.00 Free Papers Session FP5 – Professionals	Orthopedic Surgery	
08.00–08.15	Relationship between Physical Activity, Knee Muscle Strength and Gait Performance in Persons with Late Effects of Polio, <i>Cecilia Winberg (SE)</i>	FP17	11.00–11.10	Why, When, Where of Limb Lengthening, <i>Jagdish Patwa (IN)</i>	FP21
08.15–08.30	Standardization of Quantitative Data of Gait Characteristics of Post-Poliomyelitis Patients, <i>Isabella Schwartz (IL)</i>	FP18	11.10–11.20	Leg Length Discrepancy Corrected by Tibial Lengthening, <i>Neelkumar Patel (IN)</i>	FP22
08.30–08.45	Benefits of a Stance and Swing Control Long Leg Brace in Polio Survivors, <i>Merel Brehm (NL)</i>	FP19	11.20–11.30	Post-Operative Management of Limb Lengthening, <i>Jagdish Patwa (IN)</i>	FP23
08.45–09.00	Comparing the Effect of a Dorsal-Leaf-Spring AFO and a Spring-hinged AFO on Gait Characteristics in Plantarflexor Weakness – A Pilot Study, <i>Hilde Ploeger (NL)</i>	FP20	11.30–11.40	Translocation of Peroneus Longus Tendon for Calcaneus Deformity by Dr. Patwa's Technique, <i>Parth Patel (IN)</i>	FP24
09.00–10.30 Symposium SS4 – Polio Survivors	Theme: Surgery for Secondary Problems and Anesthesia		11.40–11.50	Hamstring to Quadriceps Transfer for Quadriceps Paralysis, <i>Malkesh Shah (IN)</i>	FP25
09.00–09.30	Orthopedic Surgery in Post-Polio Syndrome, <i>Matthias Schafroth (NL)</i>	SL29	11.50–12.00	Discussion	
09.30–10.00	Orthopedic Surgery in Young Polio Survivors, <i>Jagdish Patwa (IN)</i>	SL30	11.00–12.00 Free Papers Session FS2 – All Delegates	Post-Polio Survivors in Europe	
10.00–10.30	Anaesthesiology: a Risk in Post-Polio Syndrome? <i>Lise Kay (DK)</i>	SL31	11.00–11.15	The Norwegian Everyday Life, Experienced by Non-western Immigrant Women Living with Polio, <i>Nina Levin (NO)</i>	FP26
09.00–10.30 Symposium SC4 – Clinical Practice	Theme: Falls and Orthotic Devices		11.15–11.30	Strategies in Daily Occupations of Immigrants with Late Effects of Polio, <i>Iolanda Tavares Silva (SE)</i>	FP27
09.00–09.30	Twenty Years of Orthotic Adventures in Polio: An Irish Perspective, <i>Donna Fisher (IE)</i>	SL32	11.30–11.45	Physical Activity in Persons with Late Effects of Polio – A Descriptive Study, <i>Cecilia Winberg (SE)</i>	FP28
			11.45–12.00	New 20-Year Follow-Up National Survey on Polio Survivors in Norway, <i>Lillian Festvaag (NO)</i>	FP29
			12.00–13.30	Lunch/Posters	
			13.30–15.00 Plenary & Closing Session		
			13.30–13.50	How to Strengthen Collaboration with Developing Countries? <i>John Mcfarlane (IE)</i>	PL8
			13.50–14.10	Future Outlooks for the Management of Polio Survivors, <i>Jan Lexell (SE)</i>	PL9
			14.10–14.30	Award Session Best Free Paper Presentation	
			14.30–14.50	Summary of Main Conference Results, <i>Kristian Borg (SE), John Mcfarlane (IE)</i>	
			14.50–15.00	Closing, <i>Frans Nollet (NL)</i>	
			15.00–15.30	Drinks	

LIST OF POSTERS

- Summary 100:** Diving Modifications for Post-Polio Survivors? Three Case Studies, *Tamar Jacob (IL)*
- Summary 101:** Polio Australia's Annual Health and Wellness Retreats Review: The Implications for Participants on Health Literacy and Health Outcomes, *Mary-ann Liethof (AU)*
- Summary 102:** Hypnotherapy; Could it be Part of a Multi Disciplinary Approach in the Management of Post-Polio Syndrome (PPS)? *Terry Shonagh (UK)*
- Summary 103:** A Life Review for Those who Experienced Polio, *Gloria-Jeanne Anderson (USA)*
- Summary 104:** Weight Loss Using a Protein Diet? Is it Possible and Harmless in Wheelchair Bound Polio-Survivors? *Manfred Tesch (DE)*
- Summary 105:** Improved Activity and Participation in Poliomyelitis with Elbow Orthoses: More 'Right-tech' than 'High-tech'. A Case Study, *Joshua Young (UK)*
- Summary 106:** Urinary Dysfunction Among Polio and Post-Polio Patients, *Turri Mara (IT)*
- Summary 107:** More Than 50 years Follow up after Polio in Northern Italy, *Lars Werhagen (SE)*
- Summary 108:** Correlation of Arm-span and Body Height in Post-Polio Patient with Muscle Paralysis in the Lower Extremities, *Thorsten Ingemann-Hansen (DK)*
- Summary 109:** What is the Evidence for Anesthesia Problems in Post-Polio Patients, *Selma Harrison Calmes (US)*
- Summary 110:** Self-reported Impairments, Walking Limitations, Fear of Falling and the Association with Physical Activity in Persons with Late Effects of Polio, *Cecilia Winberg (SE)*
- Summary 111:** Transcranial Direct Current Stimulation (TdcS) for Sleep Disturbances and Fatigue in Patients with Post-Polio Syndrome, *Turri Mara (IT)*
- Summary 112:** Post-Polio Syndrome and Muscles Pain: Observation among 2985 patients, *Alex Shapira (IL)*
- Summary 113:** Assessments to Evaluate Activity and Participation of Polio Survivors, *Barbara Bocker (DE)*
- Summary 114:** Post-Polio Syndrome – Clinical, Demographic and Severity Evaluation Among Polio Survivors in Jerusalem, *Zeev Meiner (IL)*
- Summary 115:** Who am I? Female Polio Survivors Perceptions of Ideal and Limited Self, *Anita Atwal (UK)*
- Summary 116:** Social Consequences Among 4267 Persons, Who Contracted Poliomyelitis In Copenhagen, Denmark 1920–1954. Follow-Up For More Than 60 Years, *Lise Kay (DK)*
- Summary 117:** Long-Term Morbidity Among 4267 Persons, Who Contracted Poliomyelitis In Copenhagen, Denmark 1920–1954. Follow-Up For More Than 60 Years, *Lise Kay (DK)*
- Summary 118:** Low Prevalence of Chronic Ventilatory Insufficiency in a Cohort of Polio Survivors, *Irene Tersteeg (NL)*
- Summary 119:** The Danish Version of the Self-reported Impairments in Persons with Late Effects of Polio (SIPP), *Merete Bertelsen (DK)*
- Summary 120:** The Effect of Treatment with Immunoglobulin on Nociceptive and Neuropathic Pain in Post-Polio Patients. Three Case Reports, *Eva Melin (SE)*
- Summary 121:** Internal Consistency and Test-retest Reliability of Three Fatigue Rating Scales in Persons with Late Effects of Polio, *Ann-Sofie Ek (SE)*
- Summary 122:** Underwater Swimming Exercises for Polio Patients, *Karin Thye Jørgensen (DK)*
- Summary 123:** Rehabilitation for Persons with Post-Polio Syndrome at Akademiska Hospital, Uppsala, Sweden, *Ebba Widman Cauwenbergh and Susanne Sturesson (SE)*
- Summary 124 :** Imaging of the Post-polio Affected Muscle Architecture with Diffusion Tensor MRI: A Pilot Study, *Jos Oudeman (NL)*
- Summary 125:** Fatigue and Quality of Life in People with Post-Polio Syndrome, *Frances Quinn (UK)*
- Summary 126:** Care of Post-Polio Syndrome Affected People, *Kathrin Simon*
- Summary 127:** The Rehabilitation Plan Can Facilitate Adaptation in People with Late Effects of Polio, *Jan Lexell (SE)*
- Summary 128:** Prevalence of Post-Polio Syndrome in Valencian Community (Spain), *Vazquez Arce (ES)*
- Summary 129:** Cytokine Levels and Associations with Physical Decline over 10 Years in Post-Polio Syndrome, *Frans Nollet (NL)*
- Summary 130:** A Review of Maximum Voluntary Isometric Contraction in Polio Survivors over Four to Twelve Years, *Deirdre Murray (IE)*

PLENARY LECTURES (PL1–PL8)

PL1

POLIO ERADICATION INITIATIVE*Jan Lucas Ket, MD**Governor District 1580 Rotary International, The Netherlands*

Rotary, the greatest worldwide humanitarian service organization, with 1.2 million volunteers in 34,000 Rotary clubs, started the Polio Eradication Initiative (GPEI) in the 80's of last century. Since its launch at the World Health Assembly (WHA) in 1988, the GPEI has reduced the global incidence of polio by more than 99% and the number of countries with endemic polio from 125 to 3. More than 10 million people are walking today who otherwise would have been paralyzed. Rotarians all over the world provided not only more than one billion dollar, but also shared their networks, organizational skills and numerous hands with their partners in service to vaccinate more than 2.5 billion children. Actually Rotarians continue their efforts to eradicate polio in the next years. Rotary is involved because of the strong relation of polio with conflicts, lack of hygiene and basic education and poverty. Together with disease prevention and maternal and child health, these are Rotary's 6 areas of focus. <http://www.polioeradication.org/> <http://thisclose.endpolio.org/en> <https://www.rotary.org/en/about-rotary> <https://www.rotary.org/en/node/102436>.

PL2

POLIO ERADICATION PROGRESS*Hamid Jafari, MD**Director Polio Operations WHO, Switzerland*

Since 1988, the GPEI – a public-private partnership between national governments, WHO, Rotary International, US Centers for Disease Control (CDC) and UNICEF, and supported by key partners such as the Bill and Melinda Gates Foundation – has reduced the global incidence of polio by more than 99%. At the time, more than 125 countries were endemic, and every year, more than 350,000 children were paralysed for life. Today, only 3 countries remain polio endemic: Pakistan, Nigeria and Afghanistan, and in 2013, just over 400 cases have been reported. Of the 3 wild poliovirus serotypes, type 2 appears to have been eradicated with the last naturally occurring case detected in 1999 and type 3 has not been detected for more than 1 year. More than 10 million cases have been averted over the past 25 years, and more than 1.5 million childhood lives have been saved. However, 99% is not good enough for an eradication goal. Polio is an epidemic-prone, highly contagious disease which spreads easily from the remaining endemic areas to polio-free areas with population movements. New outbreaks are occurring in the Horn of Africa (centred around Somalia), the Middle East (centred around Syria) and Central Africa (centred around Cameroon). Polio outbreaks have public health costs associated with disease, permanent disability and death and drain financial resources. Such outbreaks will continue to occur until poliovirus has been completely eradicated in the remaining endemic countries. Failure to eradicate polio could lead to resurgence of polio all over the world. Within 10 years, the resurgence of polio will lead to an estimated 200,000 new cases, every single year. This would be a humanitarian catastrophe that must be averted at all costs. To overcome remaining barriers to eradication and to eradicate all polio, whether caused by wild polioviruses or vaccine viruses, an end game plan has been developed which calls for: 1) interrupting wild virus circulation; 2) improving routine immunization systems, introducing at least one dose of IPV into routine immunization schedules and withdrawing OPV, initially with removing the type 2 component of trivalent OPV (tOPV) and eventually all OPV post eradication of all types; 3) containment of polioviruses in facilities and certification of polio eradication; and 4) legacy planning to optimize polio eradication resources to help achieve other public health goals. Success is a question of political and societal will. Feasibility of eradication has been demonstrated time and again, most recently with success in India and the entire South-East Asia Region, which in March 2014 joined the European, Western Pacific and American Regions in being certified polio-free. Now 80% of the world's popula-

tion lives in regions that have been certified as polio free. Key actions needed from industrialized countries include: 1) providing financial support and advocacy to the overall initiative; 2) assuring all children are immunized against polio; 3) assuring travellers to polio infected areas are immunized; 4) detect polioviruses should they be introduced through appropriate work-up of cases of AFP and consideration of environmental surveillance with appropriate action if wild viruses are detected; 5) supporting introduction of IPV into developing country immunization programs to provide protection against type 2 when type 2 is removed from tOPV and to boost immunity to types 1 and 3. Achieving eradication would be this generation's gift to all future generations to never have to be burdened by this lifelong crippling disability.

PL3

PARALYSED WITH FEAR*Gareth Williams, MD ScD, FRCP, FRCPE**University of Bristol, UK*

Polio, the dreaded 'morning paralysis' which could break into any household and paralyse or kill a healthy child, became one of the iconic diseases of the twentieth century. During the 1950s, polio terrified Americans almost as much as the atom bomb. That fear was deliberately exploited to raise funds to develop a polio vaccine, in a campaign led from the White House by polio survivor Franklin D. Roosevelt. The result was two successful vaccines – but only after a no-holds-barred race between three warring scientists, Jonas Salk, Albert Sabin and Hilary Koprowski. The story of polio runs from a priest in Ancient Egypt to today's front line of the battle to exterminate polio from its last boltholes. Along the way, we meet many brilliant minds and big egos, some really bad science, treatments that killed rather than cured, and some odd decisions of the Nobel Prize Committee. Now, vaccination has pushed polio to the brink of extinction, but the recent murders of vaccination workers in Pakistan and Nigeria remind us that a happy ending is not guaranteed. And even though polio is long extinct in the West, its memory remains vivid for the millions of people around the world who live with the aftermath of this unpleasant disease and especially those who face the worsening disability of post-polio syndrome.

PL4

PATHOPHYSIOLOGY OF POST-POLIO SYNDROME – NEW AVENUES FOR TREATMENT?*Frans Nollet, MD, PhD**Department of Rehabilitation, Academic Medical Center, Amsterdam, The Netherlands*

After many years of stability following the recovery of acute poliomyelitis, muscle function may decline due to post-poliomyelitis syndrome (PPS). The prevalence of PPS in polio survivors is estimated between 40 and 60%. PPS is a diagnosis by exclusion; other explanations must be ruled out carefully. The rate of decline in muscle strength is low, approximately 2% per year and causes the gradual increase of disability. PPS symptoms may be aggravated by secondary disorders of the locomotor system, such as osteoarthritis that may result from prolonged and often deviant joint loading. Other factors that may negatively impact on symptoms and physical function are comorbidity, weight gain, and aging effects. The cause of PPS is unknown. The most widely accepted pathophysiological hypothesis is that motor neurons in the spinal cord age prematurely due to the high metabolic demands and lose their ability to maintain the large motor units that were formed in the recovery phase after the acute polio. An inflammatory process might underlie PPS since raised concentrations of cytokines have been found in the cerebrospinal fluid. The cause for this increase in inflammatory cytokines is unclear. The persistence of poliovirus parts in the genome has been debated in the past. Very recently, up regulation of inflammatory cytokines in muscles of prior polio patients has

been reported which may play a role in explaining muscle pain. So far, no pharmacological therapies are available to halt the decline in muscle function in PPS. Based on the elevated inflammatory cytokines in the cerebrospinal fluid, the effectiveness of intravenous immunoglobulins has been investigated. High-quality randomised studies, have provided insufficient evidence for wide spread use and further trials are required. The findings of inflammation in muscles may provide an opportunity to reduce symptoms. Further studies need to elucidate the cause of these elevated cytokines and their relation with chronic exercise-induced muscle damage. The lack of high quality evidence for exercise and behaviour interventions and scarcity of studies, demonstrate that more and larger trials must be done to provide the evidence for the most effective rehabilitation strategies to best preserve functioning. Since rehabilitation treatment consists of multiple interventions that are applied in concordance, studies should be designed evaluating their combined effectiveness.

PL5

TREATMENT OF YOUNG POLIO SURVIVORS IN AND OUTSIDE EUROPE

Kristian Borg, MD, PhD, Lars Werhagen, MD, PhD

Department of Clinical Sciences, Division of Rehabilitation Medicine, Karolinska Institutet, Stockholm, Sweden

After the vaccination against polio started in the late 1950s few new Swedish and Western European polio cases have been reported. This means that most of these patients are at least 60 years or older. However, due to immigration from countries where acute polio infections still are present the number of young polio patients have increased during recent years. Their origin is mainly from Africa and Asia. When analyzing the patients at our post-polio out-patient clinic, the mean age was 45 years and there was a male predominance. The most common clinical finding was asymmetrical paresis of the legs and 10% were wheel-chair dependent. Seven out of 10 suffered from pain with a mean intensity of 55/100 according to the VAS scale. In conclusion, polio patients with a foreign background are younger and are more often males when compared with Swedish post-polio patients. Otherwise, symptoms and clinical findings are the same as in the Swedish patients. However, as they come from a foreign culture often without knowledge of the native language it is a challenge to treat these patients. They are more often than native patients in need for social and vocational rehabilitation. The skill of the Western European multiprofessional post-polio teams should be used in order to implement rehabilitation for polio survivors coming from other parts of Europe and from outside Europe.

PL6

LIVING WITH POLIO IN EUROPE FROM A DIFFERENT CULTURAL BACKGROUND

Ramneek Dev, BDS, MPH

Copenhagen, Denmark

I was born in the year 1970 and contracted polio at the age of four. Being the first child in an educated middle class family of doctors, there was no reason that my family would have taken any chances and I was vaccinated against polio, but I suffered. Initially both of my legs were affected but with extensive care and physiotherapy over a period of one year my right leg and left leg knee down were paralyzed for life. There were no proper rehabilitative facilities available in the small town where I was born so most physiotherapy sessions were done at home and with the help of my parent's encouragement I started to walk with the help of braces and continued my education after a gap of one year. As the years passed by I learned to be independent and studied clinical dentistry. For my further education I went to Australia and completed Masters in Public Health. It was then that I realized the difference of living with a disability in a developing country and a developed country. Comparing the infra structure in India with that of the developed countries one can realize how difficult it is for a disabled person to survive. Most of the public buildings and public transportations are not disabled friendly. Moreover, people with disabilities are

not aware of their rights and utilization of available services is less. In low income families in a developing country a disabled child is considered a burden for the family. Though the disability policies in the European Union are in place and the citizens have facilities for their survival, there is a scope of further refinements in the law for the large number of immigrant population living with post polio and other forms of physical disabilities in Europe. New job opportunities can be created for people with limited physical abilities so that they can earn a living and not be a burden to the society. Living in Denmark for almost a year now and surviving without a job I have felt a need for reforms in the disability policies for immigrant population. I would like to close by saying that there is a lot that can be done. Some reforms should be made in the policies which would not only benefit polio survivors but also people living with other physical disabilities.

PL7

LIFE WITH POLIO IN ETHIOPIA: MY TAKE

Dagnachew Wakene, LLB, M Phil

World ENABLED, THISAbility Consulting®, Ethiopia

"How could you do this to such a cute baby?!" These words, quoted verbatim, were said to my adoptive mother by physicians who diagnosed me with polio in one of the renowned hospitals of Addis Ababa. I was 5 months old at the time. Three decades later, the words of those doctors still echo quite loud in my mother's ears. This is not an isolated story, but rather an experience widely shared among a plethora of Ethiopian families affected by post-polio syndrome. This presentation was primarily inspired by the aforementioned personal narrative. It showcases the multi-faceted aspects of living with polio in Ethiopia and answers a number of questions that matter, viz. 1) What is life like in Ethiopia for polio-survivors? Testimonies from the past and present. 2) What actual challenges do we face in our routine lives? 3) What mechanisms/services are in place to cater for our needs, and have there been any improvements thereof over the years? 4) To what extent do we participate and voice our concerns on national, regional and international development platforms? 5) And what does the future hold for polio-survivors in Ethiopia? These practical queries are addressed based on lived testimonies and perspectives of myself as well as fellow polio-survivors in my country. In a way, the presentation also sheds light about crosscutting aspects of life with polio in Sub-Saharan Africa.

PL8

FUTURE OUTLOOKS FOR THE MANAGEMENT OF POLIO SURVIVORS

Jan Lexell, MD, PhD

Department of Health Sciences, Rehabilitation Medicine Research Group, Lund University, Lund, Sweden

It is well known that many polio survivors later in life develop new symptoms, referred to as poliomyelitis sequelae, late effects of polio, or just post-polio. As there are no accurate statistics describing the number of people being affected by polio, we have no clear account of the number of polio survivors. In the EU (with a population of approximately 500 million inhabitants), the number is approximated to 600,000. With many young polio survivors in Africa and Asia, it is estimated that up to 10 million people around the world will need health care and rehabilitation during the next decades as a result of their poliomyelitis infection. Despite making this one of the most common neuromuscular conditions and a challenge to rehabilitation professionals, there is a need for further developments of the management of polio survivors. During the past decades, we have learnt a great deal about the mechanisms underlying the progressive weakness in polio survivors. We have also learnt about ways to manage symptoms, organize interdisciplinary teams, and how to support polio survivors and the families to reduce the consequences of the disability and enhance their life satisfaction. Yet, much remains to be learnt in order to comprehensively provide evidence-based and cost-effective interventions. This presentation will give an overview of future outlooks of the management of polio survivors and what type of efforts that are needed in order to provide the best possible management for polio survivors and their families.

SYMPOSIUM LECTURES (SL1–SL37)

SL1

A LIFE OF A POLIO-SURVIVOR BEGINNING AND ENDING AS A RESPIRATOR-USER*Holger Kallehauge**Danish Organization of Polio- and Accident Victims, Denmark*

It sounds as a sad song but has rather been a long and good life, very eventful, quite successful, and, with only a minor role for the respirator. It did however save my life, when I was 16 years old and at the end has until now given me more than 10 good extra years. It all started back in 1951, when I got Polio as a schoolboy and I ended as a retired High Court Judge and as President of Polio- and Accident Victims in Denmark for more than 40 years. It has been two professional lives: one with focus on the law and a very different one as a spokesman for persons with disabilities. The respirator has been an instrument of great importance both at the beginning and at the end but only as a technical aid without which, I would not have been here to day. My intervention deals with how it has been – which difficulties did it give and how has it been to depend on a machine breathing for you? How was it to live in a tank-respirator for several weeks and how did you learn to breathe again on your own? Why was it difficult to sleep without the respirator? These and other coping challenges will be described, more or less detailed. After 35 years it became a part of my post-polio syndrome to go back to use a respirator first for about 15 years only during the night and then again from 2003 24 h a day. Did it become more easy because of my initial short-time experience with a respirator? How has it been to work and to travel with a respirator? Being back on the bench as a judge, acting as a public speaker and negotiator with national and local politicians and speaking at the UN both in Geneva and New York – several roles and never boring. My respirator is now always needed, some times a little troublesome but never a foe. It gives me much more than it takes. Coping with a respirator is now just like travelling with a good friend.

SL2

VENTILATORY SUPPORT IN PATIENTS WITH POST-POLIO SYNDROME*Michael Gaytant, MD, PhD**Center for Home Mechanical Ventilation, UMC Utrecht, The Netherlands*

Polio survivors may develop ventilatory insufficiency not only during the acute phase of the disease, but also later in life. During the acute stage of poliomyelitis, ventilatory insufficiency is a consequence of the destruction of motor neurons innervating the respiratory muscles, neuronal destruction of the respiratory centre in the medulla, or both. Late onset ventilatory insufficiency may be a consequence of scoliosis or weakness of the respiratory muscles due to post-polio syndrome (PPS). Chronic ventilatory insufficiency (CVI) is one of the respiratory problems encountered by aging polio survivors and is characterized by a daytime arterial blood gas with a $PCO_2 > 45$ mmHg (> 6.0 kPa). CVI is usually preceded by nocturnal hypoventilation (NHV), which may develop insidiously and may remain unrecognized. Home mechanical ventilation (HMV) can improve quality of life by alleviating symptoms of NHV and CVI. HMV for patients with CVI is an important, growing and successful technique for reducing morbidity and mortality, especially in those with chest wall and neuromuscular diseases like patients with PPS. The primary goals of HMV:

- It should be effective: Improve ventilation by restoring gas exchange and decrease physical complaints and symptoms
- Enhance the quality of life
- Reduce morbidity and mortality
- Improve physiologic function
- Extend the duration of life
- HMV is defined as noninvasive ventilation (NIV) or ventilation via a tracheostomy for a period of ≥ 3 months on a daily basis carried out mostly in the user's home or other long-term care facility but not a hospital.

With a ventilator positive pressure is applied via the upper respiratory tract for the purpose of augmenting alveolar ventilation. NIV typically is administered through a nasal or an oronasal mask, unlike invasive ventilation through a tracheostomy tube. Since the 1990s, NIV has progressively obviated the requirement for tracheostomy and had led to the use of long-term HMV in a rapidly growing number of patients.

SL3

DYSPHAGIA AND DYSPHONIA*Päivi Tupala, Speech Language Therapist**Sunnaas Rehabilitation Hospital, Norway*

Swallowing difficulty (dysphagia), problems with voice (dysphonia) and breathing are widely considered to be symptoms attributed to post-polio syndrome (PPS). It has been estimated that 18–29% of polio survivors have daily problems with swallowing and voice. Persons who initially had polio affecting muscles in head and neck are most vulnerable for new/increased difficulties, but many individuals who didn't have swallowing problems before, are experiencing them as a symptom of PPS. New or increasing muscle weakness and general fatigue are common with PPS. Weakness in muscles contributing to breathing, swallowing, voice production and for instance coughing can lead to difficulty in all or some of the tasks these muscles contribute to. Swallowing is a result of complex, precise, fast and smooth cooperation of several muscles and nerves. Weakness in these muscles can cause severe inefficiency in swallowing. That results often to residue of food in throat after swallowing. Decreased airway protection can result to coughing, hoarse voice quality and aspiration (food/liquid in the airway). Quality of voice inclusive pitch, strength and voice endurance is also often affected, as the muscles and nerves that control swallowing also control speech and voice. Therefore it's important that a person with PPS is aware of changes he might experience regarding swallowing and voice. Also professionals should be aware of the importance of regular evaluation of dysphagia and dysphonia in this population. Clinical evaluation including assessment of oral-motor skills, voice and breathing and mealtime observation is important, as well as a thorough anamnesis. Instrumental examination gives critical information both of the severity and nature of swallowing difficulty, but is also a key to customize treatment and compensatory techniques. By modifying positioning, eating habits, consistencies and using swallowing techniques can help the person to maintain safe swallowing and to avoid fatigue under meals. The social aspect of dysphagia and ability to communicate is also of great importance for every polio survivor. Therefore everybody who experiences difficulties with swallowing or/and voice should be assessed at regular intervals.

SL4

TREATMENT OF YOUNG IMMIGRANTS IN EUROPE*Kristian Borg, MD, PhD, Lars Werhagen, MD, PhD**Department of Clinical Sciences, Division of Rehabilitation Medicine, Karolinska Institutet, Stockholm, Sweden*

After the vaccination against polio started in the late 1950s few new Swedish and Western European polio cases have been reported. This means that most of these patients are at least 60 years or older. However, due to immigration from countries where acute polio infections still are present the number of young polio patients have increased during recent years. Their origin is mainly from Africa and Asia. When analyzing the patients at our post-polio out-patient clinic, the mean age was 45 years and there was a male predominance. The most common clinical finding was asymmetrical paresis of the legs and 10% were wheel-chair dependent. Seven out of 10 suffered from pain with a mean intensity of 55/100 according to the VAS scale. In conclusion, polio patients with a foreign background are younger and are more often males when compared with Swedish post-polio patients. Otherwise, symptoms and clinical findings are

the same as in the Swedish patients. However, as they come from a foreign culture often without knowledge of the native language it is a challenge to treat these patients. They are more often than native patients in need for social and vocational rehabilitation.

SL5

TREATMENT OF YOUNG POLIO SURVIVORS IN TURKEY

Arzu On, MD

Department of Physical Medicine and Rehabilitation, Ege University Medical Faculty, Izmir, Turkey

Turkey has some special features regarding poliomyelitis. It is a big country with over 80 million population. Most of polio survivors were affected by acute polio during the epidemics in the 1970s, and Europe's last case of indigenous wild poliomyelitis occurred in eastern Turkey in 1998. Moreover, as Turkey is located between Europe and Asia, it is on the way of migrations from these countries to Europe and accommodates a large number of immigrants from polio-endemic countries. That means that there are many polio survivors and many of them are still very young. It is estimated that, currently there are 5,000 polio survivors younger than 40 years old in Turkey, who had already developed post-polio syndrome (PPS) or who are still candidate of having PPS. Due to recent advances in medical rehabilitation, emergency medicine and consumer education, they will survive long enough to experience both the rewards and challenges of being young. The challenges that young polio survivors may face are quite different than those faced by older survivors. They may face challenges of finding a new job, maintaining their jobs, getting married, giving a birth etc. Lifestyle adjustments to reduce excessive metabolic demands on muscle is more difficult in active, young polio survivors. Thus the treatment strategies should cover all aspects of life and must be specific to an individual's need. Both PPS and other potential problems related with the aging process should encourage preventive steps and services. In addition to seeing appropriate health professionals to alleviate and manage the late effects of polio, their overall sense of wellness and ability to participate in life should be improved. Post-polio support groups as well as individual and family counseling are important to prevent social isolation and emotional reactions to the late effects of polio. Change in lifestyle, prevention of osteoporosis and falls, prescription of individualised exercise programs, dietary counselling, modification of orthotics, treatment of other disorders unrelated with polio, treatment of PPS symptoms, job modifications are some of the important issues in young polio survivors.

SL6

CORRECTIVE SURGERY FROM A PATIENT CENTERED PERSPECTIVE FOR POLIO RESIDUALS IN INDIA

Mathew Varghese, MBBS, MS

St Stephen's Hospital, Tis Hazari, Delhi, India

For the last 3 years no new cases of paralytic poliomyelitis have been reported from India. However, there are a large number of patients in the country with residual problems resulting from paralytic poliomyelitis. True numbers are not known but official National Sample Surveys peg the numbers from 2–3 million. Many of them can be improved with corrective surgeries. Surgical procedures for these patients can be categorized into 4 different groups: Deformity correction (which is the most commonly done procedure), Stabilisation procedures (especially for the foot), Balance of muscle power by tendon transfers especially in upper limbs, and Correction of limb length discrepancies. Over the last 27 years we have been treating patients with paralytic poliomyelitis with regular follow-ups. With surgeries in over 14–15,000 patients, there has been a paradigm shift in our approach to these patients' rehabilitation during these years of follow-up. These relate to our social approach to these patients and surgical techniques adopted. Merely providing free services will

not ensure that patients will avail the services provided. Admissions have to be prioritized by reserving beds, improvisations in surgical procedures have to be done to facilitate activities of daily living at home environment. Therapy and gait training are done as in patients to overcome barriers of transportation. Repair facilities for calipers (Orthotic aids) have to be provided as these are not available at village level. Most patients have activities on the floor in the home environment, so keeping knee movements intact is important. This is difficult in the older patients with flexion deformities of the knee. So conventional methods have to be modified to ensure that knee range of movement exercises are continued during deformity correction. Many come with severe deformities requiring challenging surgical procedures for correction. This paper discusses the evolution of our approach to the rehabilitation of these patients.

SL7

POLIO SURVEILLANCE: BASIS FOR SUCCESSFUL ERADICATION

Harrie van der Avoort, PhD

RIVM, National Institute of Public Health and the Environment, Bilthoven, the Netherlands

Poliovirus infection fulfills all biological criteria for successful eradication. Poliovirus causes an acute disease only in humans, can survive outside the human body for only a limited time. Poliovirus transmission is based on direct contact between humans or between humans and their excreta. Two vaccines are available that prevent illness and limit poliovirus circulation. The clinical symptoms caused by poliovirus infection are diverse ranging from acute flaccid paralysis in (mostly, but not restricted to) limbs, but also meningitis and encephalitis, to more mild disease, like neck stiffness, fever, "flu-like" disease. Ninety percent of infections are subclinical. Not every case of the classical polio paralysis is caused by poliovirus, and therefore various systems for surveillance have been developed, to monitor spread of the virus and to measure the effect of vaccination. Pros and cons of these systems will be discussed. Poliovirus surveillance must continue at the highest level even beyond detection of the last poliovirus case for at least 3 years to document the successful eradication of poliomyelitis, a major public health achievement.

SL8

DEVELOPMENT OF INACTIVATED POLIO VACCINE BASED ON ATTENUATED SABIN POLIOVIRUS STRAINS: MANUFACTURING, CLINICAL TRIALS AND TECHNOLOGY TRANSFER

Wilfried Bakker, PhD, Yvonne Thomassen, MSc, Pauline Verdijk, PhD, Ahd Hamidi, MSc

The Netherlands Institute for Translational Vaccinology (Intravacc), Bilthoven, The Netherlands

Worldwide efforts to eradicate polio recently caused a strategic change in polio vaccination recommendations. A switch from oral polio vaccine (OPV), which can cause circulating and virulent vaccine derived polioviruses, to inactivated polio vaccines (IPV) is foreseen. However, current IPV supply is limited, and the cost price is relatively high when compared with OPV. To enhance worldwide production of affordable IPV, a manufacturing process using attenuated (Sabin) poliovirus strains, instead of wild-type polioviruses, is pursued. The resulting Sabin-IPV (sIPV) was developed for technology transfer to local manufacturers. By using weakened polioviruses in production, the risk of facilities related outbreaks can be reduced. Three dose levels of sIPV, were produced for clinical evaluation with respect to the safety and immunogenicity. To explore dose-sparing opportunities, sIPV was also adjuvanted with aluminium hydroxide. The highest dose level of both plain and adjuvanted sIPV were first evaluated in a double-blind, randomized, controlled, phase I trial in healthy adults. This trial was followed by a dose-escalation,

double-blind, randomized, phase I-IIa trial in infants. In both trials, a reference group received conventional IPV. Virus-neutralizing titers against both Sabin- and wild-type strains were determined before and after (the last) vaccination. The incidence of local and systemic reactions was not influenced by the dose level of the vaccines and was comparable with the conventional IPV. In all adults, an increase in antibody titer over pre-existing antibodies for all types of poliovirus was observed after vaccination. Seroconversion rates in infants were 95–100% for Sabin- and wild-type strains. Three doses of sIPV or adjuvanted sIPV in infants induced high virus geometric mean titers, both against Sabin- and wild-type strains, even at a low dose level. In conclusion, sIPV and adjuvanted sIPV were immunogenic and safe both as booster dose in adults and for primary immunization of infants. Currently, the sIPV technology is transferred to emerging manufacturers in low- and middle-income countries. Intravacc has licensed the sIPV technology to a number of selected partners, and will be providing training and support. In parallel, continued process optimization can contribute to increase the sIPV quantities available for the post-eradication era.

SL9

PERSISTENCE OF POLIOVIRUS GENOME IN POLIO SURVIVORS DIAGNOSED WITH POST-POLIO SYNDROME

Andreina Baj, MD¹, Martina Colombo, MS¹, Giuseppe Maccari, PhD², Andrea Nauti, MD¹, Giorgio Bono, MD¹, Merja Roivainen, PhD³, Antonio Toniolo, MD¹

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Introduction: The only evidence for persistent poliovirus infection has been found in individuals with B lymphocyte deficiencies (and low or absent immunoglobulins). These represent a virus reservoir. Incubation of poliomyelitis is short, but can be over 10 years (DeVries et al., 2011). Thus, poliovirus can produce prolonged infections before causing symptomatology. The origin of post-polio syndrome is poorly understood. Persistent or new inflammation in meninges, spinal cord and muscles was detected in PPS (Miller, 1995). Inflammatory infiltrates suggest: persistent poliovirus infection, autoimmune attack on CNS targets, increased vulnerability of damaged tissue to further infections. We investigated the possibility of a persistent infection in PPS patients. **Aims, methods and results:** PPS cases diagnosed according to EFNS criteria were investigated ($n=96$) together with their family members ($n=45$) and controls (26 blood donors and 25 pathologic controls). Specimens: peripheral blood leukocytes, cerebrospinal fluid, live cells of duodenal mucosa, skeletal muscle, peripheral nerve. Poliovirus genomes were detected in 81/96 (86%) PPS patients vs. 3/96 controls (3.1%). Type 1 poliovirus was most frequent (61% of cases), type 2 (12%), type 3 (9%). Other cases were not typed. Based on anamnesis, 15/81 cases were attributed to vaccination. Epithelial cells infected with poliovirus isolates obtained from PPS patients produced virus capsid proteins and increased concentrations of the MCP-1 chemokine. Serum immunoglobulin levels were measured in cases and controls. Levels of IgG1, IgG2, IgG4 and IgA were significantly reduced in PPS cases and their family members. IgM levels and titers of poliovirus neutralizing antibodies were not significantly different among cases and controls. **Conclusions:** Residual poliovirus activity is frequent in PPS patients and may have pathogenic significance. Poliovirus infection is not transmitted by PPS cases to their family members, a relevant finding for public health. Effective treatments for PPS are missing (Farbu, 2010; Koopman et al., 2011). It would be beneficial to identify individuals with chronic poliovirus infection and treat them with antivirals and/or antiviral antibodies in order to avoid PPS development or block its progression. Such compounds are not yet ready for clinical applications. Trials are needed to test treatments potentially capable of eradicating poliovirus in chronic carriers.

SL10

AGING AND MUSCLE FUNCTION INCLUDING SARCOPENIA

Jan Lexell, MD, PhD

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With increasing age, the human skeletal muscle undergoes a number of quantitative and qualitative changes related to reductions in muscle mass and muscle strength and alterations in the quality of remaining muscle tissue, commonly referred to as sarcopenia. It is now widely accepted that sarcopenia starts around the age of 50 and leads to reduced functional capacity for the older individual, with an increased risk of falls, fractures, and dependency. Our knowledge of the underlying mechanisms of these changes has grown during the last decades, and so has our knowledge of the effects of physical activity and training on the structure and function of the aging muscle. For someone who acquired polio in their youth and have already lost a considerable amount of muscle mass, increasing age can have an even more profound effect on muscle structure and function. For those who have mild sequelae from their acute polio infection, aging may not have the same effect. However, regardless of the severity of their prior polio, increasing age and the effects of it, is one of the major factors leading to the progressive reduction in muscle structure and function that seen in people with post-polio syndrome. This presentation will summarize our collective knowledge about aging and muscle function, sarcopenia and its underlying mechanisms, and how this can be linked to the neuromuscular changes that are seen post-polio syndrome. The presentation will also highlight the importance of physical activity to counteract sarcopenia.

SL11

OSTEOPOROSIS IN POLIO SURVIVORS

Helena Burger, MD, PhD

Linhartova, Ljubljana, Slovenia

Osteoporosis (“porous bones”, from Greek: οστούν/ostoun meaning “bone” and πόρος/poros meaning “pore”) is a progressive bone disease that is characterized by a decrease in bone mineral density (BMD) which can lead to an increased risk of fracture. There are several risk factors for osteoporosis, including reduced physical activity and muscle weakness. Both of them are frequent in poliomyelitis survivors and several authors describe increased incidence of osteoporosis among them (1–4). Specially they found decreased BMD of femoral neck (1, 4). These studies also found that the main predictors for osteoporosis in polio survivors are decreased muscle strength and non regular exercises (1, 4). In spite of high percentage of persons with osteoporosis only few received anti-resorptive therapy (3). The main and most dangerous consequence of osteoporosis are fractures. Osteoporotic fractures occur in situations and falls that normally does not break bone, we call them low impact fracture. Authors reported that 50 up to 74% of polio survivors had fallen at least once in the previous year (5–7). Several of them need medical attention and resulted in fractures (7). Fractures needed immobilisation and further decrease physical activity and the circle is closed. From a rehabilitation point of view it is important that we are aware about increased incidence of osteoporosis and falls in polio survivors and to educate them about the disease and its consequences, advise them appropriate activity and prescribe them appropriate drugs and technical aids.

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SL12

MEDICATION FOR COMORBIDITIES; EFFECTS IN POST-POLIO SYNDROME?

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Effects of medication for comorbidities in post-polio syndrome (PPS) have not been evaluated in randomized controlled studies. However, this does not necessarily mean that persons with PPS respond like everyone else to any sort of medication. Theoretical considerations and experience indicate that in some areas persons with PPS may be at special risk. The acute polio has left polio survivors with fewer nerves in the spinal cord and more central parts of the nervous system (for example centers for regulation of blood pressure, pulse, and sleep). Furthermore the remaining nerves may, to some degree, have a suboptimal function. Consequently, medication acting by interfering with nerve junctions may have a more vigorous effect than normally observed. Various medicines act this way, the most common being in the field of tranquilizers, sleeping medication, anti-depressants, alfa- and betablocking agents, and various medication used for anesthesia. This does not imply that all polio survivors cannot have the above-mentioned medication; it only means that the medicine should be initiated with a low dose, and the patient carefully followed to adjust the dose in relation to the effect/side effects that turn up. Some medication may have side effects that are more problematic for polio survivors. For example medicine that is neurotoxic. As polio survivors have fewer nerves, an additional reduction in nerve function may have a much more serious effect, that seen in persons with a normal number of nerve cells. Some types of chemotherapy and of antibiotics have this sort of side effect. Various medicines have muscle pain and muscle weakness as side effects. The most common are the “-statines” taken for elevated cholesterol level. These side effects seem to occur more often in polio survivors, and with more serious results, as it adds to the symptoms they already experience. The side effects usually disappear within weeks after withdrawal. Pravastatin and Rosuvastatin are reported not to have such side effects. Calcium antagonists used for hypertension and cardiac symptoms may also result in muscle pain and muscle weakness. In conclusion, polio survivors may take almost any form of medicine provided the dose is carefully adjusted, neurotoxic medicine however may give permanent nerve damage and should be avoided as far as possible.

SL13

DIAGNOSTIC CRITERIA FOR POST-POLIO SYNDROME

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Post-polio syndrome (PPS) can only be defined on clinical grounds. Published criteria from the European Federation of Neurological Societies in 2006 have proven to be workable in clinical practice. These require the following to be fulfilled: 1) A prior episode of paralytic poliomyelitis with residual motor neuron loss (which can be confirmed through a typical patient history, a neurologic examination, and, if needed, an electrodiagnostic exam); 2) A period of neurologic recovery followed by an interval (usually 15 years or more) of neurologic and functional stability; 3) A gradual or abrupt onset of new weakness or abnormal muscle fatigue, decreased endurance, muscle atrophy, or generalized fatigue; and 4) Exclusion of medical, orthopedic, and neurologic conditions that may be causing the symptoms. Frequently, however, PPS patients present with co-morbidities and the impact of these requires care-

ful clinical assessment to avoid confusion in diagnosis. This is especially important where investigational techniques and interventions are being assessed in clinical research. The confirmation of the diagnosis of previous polio often raises difficulties especially when patients were minimally affected by the original infection or were left with minimal or negligible long term deficits. This may have significant social and financial implications for patients. The objective assessment of new weakness, abnormal muscle fatigue, decreased endurance and muscle atrophy all present a significant challenge in the clinic and the use of instruments of measurement and serial assessments is an area for ongoing evaluation. Determining a threshold at which symptoms become truly indicative of new pathological processes still depends on clinical judgement and has been a controversy surrounding PPS since its earliest description. Efforts to more accurately define this are needed.

SL14

DIFFERENTIAL DIAGNOSIS OF POST-POLIO SYNDROME AND THE ROLE OF MUSCLE IMAGING

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The general criteria for post-polio syndrome (PPS) are: new muscle weakness and fatigue in patients with past paralytic polio, with at least 10 years of functional stability, and no other medical or neurologic conditions that can explain the new symptoms. Since there are many conditions which can manifest with symptoms and signs resembling PPS and since there is no specific diagnostic test the diagnosis PPS is one of exclusion. In that respect there are some key questions if patients present with a history of new muscle weakness or fatigue and mention a previous history of polio: Is there a credible history of polio? Are there sequelae? If patients with new muscle weakness insist that they have been afflicted with poliomyelitis and have recovered completely electromyography looking for spontaneous muscle fiber activity of signs of reinnervation or muscle imaging showing sub-clinical replacement of muscle tissue by fat can be helpful ancillary investigations. Alternatively there may be patients claiming to have had another neurological condition such as Guillain-Barré syndrome who do turn out to be polio survivors. Here too muscle imaging can be useful. In clinical practice one can be faced with patients with a neurological condition which is found to be related to previous polio during the diagnostic process (e.g., laryngeal stridor in a patient who has had bulbar polio, swallowing difficulty in patients in whom the pharynx was affected during the acute polio). There are also PPS-patients who develop a neurological condition which is unrelated to polio (e.g., multiple sclerosis, brachialis plexopathy, amyloid myopathy, ALS). If there is a rapid disease course, consider other diagnoses, e.g. amyloidosis, motor neuron disease. And finally, there are also PPS-patients who develop a neurological condition which is indirectly related to previous polio (ganglion, sciatica caused by lumbosacral radiculopathy, bursitis coxae, osteoarthritis). Therefore, if pain is a prominent complaint, consider radiculopathies or entrapment neuropathies and perform EMG and if necessary imaging of the affected body part. Keypoints: 1. History taking carefully addressing the polio infection, the involvement of muscles at that time and the sequelae is crucial. 2. Careful history taking about the current complaints (new muscle weakness, progression rate, association with pain, sensory disturbances). 3. EMG and imaging and in some cases blood tests can be an adjunct to the clinical examination.

SL15

THE ROLE OF EMG INVESTIGATIONS IN POST-POLIO SYNDROME

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It is well established that the diagnosis of post-polio syndrome (PPS) is a clinical diagnosis. Thus, the value of EMG studies in the patients with poliomyelitis has not been universally accepted and been controversial. However, if these studies are performed with a specific purpose in mind, they give very important information. EMG studies are diagnostic techniques that are used to evaluate the structure of a motor unit. They give very important informations in poliomyelitis in which structural alterations of the motor unit occurs. Conventional needle EMG is the most commonly used diagnostic study in polio survivors, either in routine clinical practice or for research purposes. Macro EMG is a newer technique that can assess the size of the entire motor unit. We can also estimate the number of motor units in a muscle, by using different motor unit number estimation techniques. Many polio survivors continue to have abnormalities on EMG studies whether or not they are having new symptoms. These studies reflect chronic denervation and ongoing reinnervation in the polio-affected muscles. Amplitude, duration and number of phases of the motor unit potentials are increased in both conventional and macro EMG, and recruitment rate is decreased, due to loss of motor units, and increased number and size of muscle fibers in a motor unit. Although paresis is an obvious clinical marker of previous paralytic polio infection, EMG studies have important diagnostic role, either in documenting or excluding motor neuron involvement compatible with previous paralytic polio. This is also true for the patients who had initial paralysis or weakness and experienced complete clinical recovery. Subclinical motor neuron involvement may be detected in the muscles that were considered un-affected during the acute poliomyelitis but were indeed affected and completely recovered during recovery process. Despite the fact that EMG studies cannot be used to diagnose PPS, they are helpful to document the evidence of motor neuron involvement or to determine or exclude other neurologic disorders that might mimic the new symptoms of PPS. These studies also contribute greatly to our understanding of the pathophysiology of neuromuscular junction dysfunction after acute poliomyelitis.

SL16

RESILIENCE AND PSYCHOLOGICAL REACTIONS IN POLIO SURVIVORS

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In health and rehabilitation research there has been a shift from being preoccupied with “risk” factors such as shortcomings and pathology, described by Olkin as “the burden literature of disability”, to identifying factors that protect against adverse outcomes. The construct of resilience could be the key to explaining resistance to risk across the lifespan and how people ‘bounce back’ and deal with severe adversities experienced from childhood to older age, such as disabilities or ill-health. Despite the fact that there is not a single, universal definition of resilience, there are similarities among the qualities used to characterize human resilience. These include (a) psychological and dispositional attributes, (b) family support and cohesion, and (c) external support systems. Studies on resilience have explored serious life-adversities such as bereavement, different kinds of trauma, physical illness and severe injuries in a longitudinal perspective. Many of the famous studies on resilience are longitudinal dealing with how children who have been exposed to serious adversities manage their lives. Results show that at least 50% and up to 70% of the high risk children not only function well in society, but they are also confident, competent and caring. This is in contradiction to earlier theories within developmental psychology which emphasized that the break in relation between child and mothers (denoted as child deprivation) has decisive influence upon the child’s development and could lead to emotional «coldness», superficial social relations and restricted intellectual development. Very few studies in high risk children have, however, focused on congenital or early acquired disabilities, such as contracting polio. The aim of this presentation is to explore some of the psychosocial studies on polio survivors that

have been conducted, among others from Sunnaas Rehabilitation Hospital, and try to analyze them within the framework of human resilience. Some studies concerning patients with long-standing physical disabilities will also be mentioned in order to highlight the points of view. Methods of assessing resilience are presented. Further, implications for treatment according to different trajectories of adaptation or resilience faced with severe physical disabilities are outlined.

SL17

COGNITIVE BEHAVIOURAL THERAPY

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The efficacy of Cognitive Behavioural Therapy (CBT) to reduce fatigue and improve activities and quality of life in patients with post-polio syndrome (PPS) is currently being studied in a multi-centre, single-blinded, randomized controlled trial (the FACTS-2-PPS trial). In this symposium on psychological interventions, the content of the CBT protocol of the FACTS trial will be outlined. The CBT protocol was originally developed for treating Chronic Fatigue Syndrome and it was adapted to target frequently reported perpetuating factors of fatigue in people with PPS. The frequently reported perpetuating factors are: dysfunctional cognitions with respect to the disease, pain and fatigue; dysfunctional attention to fatigue and pain; deregulation of sleep; deregulation of physical, social and mental activities and low social support and negative social interactions. CBT is personalised and based on an individual assessment of identifying perpetuating factors. The most frequently used modules fitting the psychological themes of people with PPS will be discussed.

SL18

HOPE AND WELL-BEING OF PATIENTS WITH POST-POLIO SYNDROME: IMPLICATIONS FOR PSYCHOTHERAPY

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Context: Individuals with post-polio syndrome need to cope with the re-emergence of old and new symptoms after years of adjustment to the consequences of polio. Traditionally, their psychopathology was highly addressed in research and their educational, occupational, and familial achievements have been attributed to compulsively competitive behavioral patterns. *Objective:* To determine the effect of hope on quality of life of individuals with post-polio syndrome and to develop a psychotherapy paradigm based on elevating hope. *Methods:* An evaluation of the associations between hope and quality of life of individuals with post-polio syndrome. Sixty-one consecutive patients attending a post-polio clinic and 40 age-matched controls filled in questionnaires assessing proactive coping, hope and quality of life. *Main Outcome Measures:* Correlations and prediction models between levels of hope and quality of life. *Results:* Post-polio patients had lower quality of life (Total SF 36 score=38.7, SD=19.3) than age-matched controls (Total SF 36 score=79.6, SD=17.7). Hope was positively associated with physical and mental health in the post-polio group but not in the control group. In the multivariate analysis, hope and work predicted higher quality of life only in the post-polio group. *Conclusions:* Hope has a unique benefit for post-polio patients in terms of elevating their physical and mental health, which are major determinants of quality of life. Therefore encouragement of hope, by working with patients to define meaningful and attainable goals is a major goal in psychotherapy of individuals with post-polio syndrome. Work is a major component to which goals ought to relate.

SL19

MANAGING PAIN IN POLIO

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According to recent studies, pain is a major symptom in polio sequela and post-polio syndrome and affects the quality of life of polio survivors. Although pain may sometimes be attributed to musculoskeletal consequences due to secondary mechanical causes (impingement syndromes, musculotendinous, degenerative arthritis, scoliosis...), in many situations, the cause of pain in post-polio remains unexplained. The nociceptive and neuropathic characteristics of pain should be carefully assessed, thus, appropriate treatments will be undertaken. This workshop aims at discussing the evaluation of pain in polio survivors and the management of pain treatment in real clinical situations.

SL20

WHAT TO DO WITH FATIGUE PROBLEMS IN POST-POLIO SYNDROME?

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Background: Fatigue is one of the most common symptoms in PPS. *Aim:* To characterize primary and secondary sources of fatigue in post-polio syndrome (PPS) and to give an overview of different management methods. *Method:* Literature review and clinical observations. *Result:* Fatigue is a complex phenomenon without an exact definition. According to ICF fatigue is an interaction of health status and disease, body function and structure, activity and performance and participation and psychological factors. Fatigue is one of the most common symptoms in PPS. Fatigue is also a primary symptom in other medical and neurological conditions and a secondary symptom in conditions like depression, pain and stress. In the general population, 12–25% experience fatigue. Healthy individuals experience fatigue after physical and/or mental exhaustion, inactivity and sleep deprivation. With increasing age the decreasing number of motor neuron leads to increasing muscle weakness, a process that is more pronounced in polio patients. There are several types of fatigue, like general-, mental-, cognitive-, psychological-, physical- and muscle fatigue. The subjective experience of fatigue is dependent of the overall well-being, coping mechanism, attribution and social circumstances. All these factors interact. Management of fatigue in PPS are mostly pacing, training, life style changes, acceptance of walking aids and condition, pain reduction and in some cases medical treatment. There is a need to better understand the fatigue phenomenon both in relation to the fatigue in general but also in relation to PPS. There is also important to develop new management methods of fatigue.

SL21

SLEEP AND NEUROMUSCULAR DISEASE

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Neuromuscular disease, e.g. post-polio syndrome, may affect sleep in several ways. Muscle weakness can influence sleep breathing which may give rise to an obstructive sleep breathing disorder. Furthermore muscle weakness may influence sleep breathing excursions negatively giving rise to desaturations which may lead to arousals. Both above-mentioned sleep breathing disorders can cause excessive daytime sleepiness which may wrongly be interpreted as fatigue. On the other hand pain in the weaker muscles may cause disruption of sleep by causing awakenings. Also the psychological consequences of the presence of a chronic neuromuscular disease, such as the post-polio syndrome, will have a negative impact on sleep quantity and quality due to an increased number spontaneous

awakenings. The combination of both sleep breathing disorder and the psychophysiological aspects on sleep can have an important influence on the overall quality of life and feeling of wellbeing of any patient affected by a neuromuscular disorder. Treatment of a sleep breathing disorders is relatively simple. A good treatment can and will have an important positive influence on sleepiness, fatigue and thus the quality of life of these patients. Distinguishing between fatigue and sleepiness can only be done using an appropriate polysomnographic recording to exclude or demonstrate the existence of a sleep disordered breathing syndrome. It is thus advisable to screen for both above-mentioned sleep disorders in all patients suffering from post-polio syndrome.

SL22

BEST PRACTICES FOR POST-POLIO SYNDROME – REHABILITATION

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In 2011, a systematic Cochrane review on treatment for post-polio syndrome (PPS) has been published, including the evidence from (quasi)-randomized controlled trials (RCTs). In that same year, the European Federation of Neurological Societies (EFNS) task force published a revised guideline for diagnosis and management of PPS, based on the evidence obtained from RCTs, uncontrolled studies, case series, case reports, and expert opinion. A first update of the Cochrane review is being prepared, in which new trials published after September 2010 will be included. Although both papers used different methods to summarize research evidence, the conclusions on the effectiveness of interventions for PPS are mainly comparable. There is evidence that intravenous immunoglobulin (IVIG) has no beneficial effect on activity limitations, and there is inconsistency in the evidence for effectiveness on muscle strength and pain. Results of one trial provide evidence that lamotrigine might be effective in reducing pain and fatigue, resulting in fewer activity limitations. Data from two single trials suggest that muscle strengthening and static magnetic fields are beneficial for improving muscle strength and pain, respectively, with unknown effects on activity limitations. Finally, there is evidence that modafinil, pyridostigmine, amantadine and prednisone are not beneficial in PPS. Due to the differences in methodology used, the conclusions with regard to effectiveness of rehabilitation in a warm and cold climate differ between the Cochrane review and the EFNS guideline. Furthermore, in the EFNS guideline, aerobic exercise, hydrotraining, respiratory muscle training, respiratory support, lightweight carbon orthoses, lifestyle changes and weight control are recommended for patients with PPS. These recommendations are based on consensus within the task force group on studies that could not be included in the Cochrane review. *Key point 1:* The EFNS guidelines for diagnosis and management of PPS and the Cochrane review on treatment for PPS provide guidance for daily clinical practice. *Key point 2:* IVIG, lamotrigine, muscle strengthening exercises, and static magnetic fields may be beneficial in treating symptoms of PPS. *Key point 3:* Due to insufficient good quality data and lack of randomised studies, it is impossible to draw definite conclusions on the effectiveness of interventions for PPS.

SL23

EXERCISE INTERVENTIONS IN POST-POLIO PATIENTS

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From having been a rather restrictive view on physical training in persons with late effects of polio, it has become more positive during the last 20–30 years. Thus, systematic training has been incorpo-

rated in the clinical management of post-polio patients. Still, there are few studies with acceptable scientific evidence. In this review published reports dated after 1985 will be summarized. There are 8 reports on resistance training, of which only two are RCT, and 6 with endurance training, of which 4 could be characterized as RCT. In one additional uncontrolled study both endurance and resistance training are included. Ninety-six patients patients were training in the resistance training studies. The muscle strength increased, usually specifically measured in the type of exercise being trained, and in an order usually seen in healthy persons. In one RCT study there was indication of an increased voluntary motor drive by training. Ninety-three patients were training in the endurance training studies. In most studies, there was an increase in peak oxygen uptake or other indications of improved capacity as reduced heart rate at submaximal workload. In addition, reduced energy consumption at exercise was noted. Improvement in subscales in Nottingham Health Profile was recorded. In one study hospital-based and home-based programs were compared with more positive effects of the hospital-based supervised program. In two of the RCT studies there were significant differences after the intervention period between training and control groups, in a third movement energy was improved. Pool exercise was appreciated in a study, where also psychosocial effects of training were reported. No substantial adverse effects on muscle function were noted in either the resistance or the endurance studies. There is definitely need for larger RCT studies and including patients groups with different level of polio affection. Outcome measures not only on muscle and endurance function but also on activity and participation should be included. So far principle recommendations for different groups of patients have to rely on muscle strength and electrophysiological data. Such a scheme for choosing the level of training intensity will be presented. Aspects on pacing and rest periods will also be given.

SL24

INTERDISCIPLINARY TEAMWORK AND REHABILITATION PLANS

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Like many other life-long slowly progressive disabilities, people with post-polio syndrome (PPS) benefit from being admitted to a team specialised in the condition. Even if the disability affects daily life, it is possible for people with PPS, with the support of rehabilitation professionals, to go through a process of change leading to a better life. During such a rehabilitation process, a team with several professionals work in close collaboration with the person and his or her family to achieve the desired goals and optimal outcome. The common goal is to reduce self-perceived disability by providing a variety of interventions and thereby maximize each individual's physical, mental and social potential. The teamwork is facilitated by a clear strategy and the use of a rehabilitation plan. In this presentation, the goal-oriented, comprehensive interdisciplinary rehabilitation process for people with PPS will be presented. Research findings will be presented indicating that interdisciplinary rehabilitation can support persons with PPS to adopt self-management strategies and thereby experience a positive turning point in life, together with the experiences of using a rehabilitation plan as a tool to facilitate such a process of change.

SL25

THE IMMUNOBIOLOGY OF POST-POLIO SYNDROME

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The most commonly accepted explanation as to the cause of post-polio syndrome (PPS) is the premature attrition of motor neurons, especially those supporting large motor unit territories. After the

acute polio attack, the surviving motor neurons oversprout to effectively reinnervate and recruit within their motor unit territory many muscle fibers left denervated from the loss of the neighboring motor neurons. After several years however, these overfunctioning neurons cannot keep up with the metabolic needs required to support large motor units, and several distal nerve terminals degenerate resulting in new muscle weakness and fatigue. Apart from this attrition process, there is evidence that some of the surviving motor neurons were marginally affected during the original poliovirus infection and survived the acute attack. This has raised the possibility that within the survived neurons there may be an immune or inflammatory reaction either to non-infectious viral remnants that escaped immune surveillance or to newly exposed neuronal neo-antigens, that might contribute to the ongoing neuronal dysfunction and, subsequently, to the manifestation of some symptoms in PPS patients. This possibility has been based on the following observations: a) increased expression of mRNA for proinflammatory cytokines TNF- α , INF- γ , IL-10 and IL-4 in cerebrospinal fluid (CSF); b) perturbation of immunoregulatory T cells; c) oligoclonal bands in the CSF of PPS patients; d) perivascular and lymphocytic infiltrates and active gliosis in the spinal cord even after 30 years from the original polio attack; e) spotty areas of inflammation in the muscles of post-polio patients with upregulation of MHC-I or II class antigen and f) treatment with IVIg suppresses proinflammatory cytokines in the CSF and results in some clinical improvements that positively affect quality of life measures. The significance of these immunological signals will be discussed in conjunction with their clinical relevance and the rationale to treat PPS with immunomodulating agents along with the need to perform clinicopathologic correlations.

SL26

TREATMENT OF POST-POLIO SYNDROME WITH IMMUNOGLOBULINES

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An inflammatory process in both cerebrospinal fluid and peripheral blood have been shown in patients with post-polio syndrome (PPS). Immune-modulating therapy with intravenous immunoglobulin (IVIg) decrease the inflammation and gives a clinical effect on muscle power, increased activity, quality of life especially for vitality and pain with a duration of approximately one year. So far no biomarker correlating to a positive outcome of the IVIg treatment has been reported. Thus, it is of importance to characterize responders and non-responders in order to be able to give the treatment to patients who will benefit from it. A speculation is that pain relief may be the primary effect of IVIg. A finding of an up-regulation of prostaglandin enzymes mPGES and cPGES as well as Cox 1 and Cox 2 in blood vessels in muscle may be the background for "post-polio pain" and may be the target for IVIg. This finding opens new possibilities for treatment of post-polio pain.

SL27

LOSS OF MOTOR UNIT SIZE AND QUADRICEPS STRENGTH OVER 10 YEARS IN POST-POLIO SYNDROME

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Objective: To investigate whether strength decline in post-polio syndrome (PPS) results from excessive distal axonal degeneration of enlarged motor units. *Methods:* We assessed changes over 10 years in isometric quadriceps strength, mean motor unit action potential (MUAP) size, root mean squared (RMS) amplitude, and level of interference (LOI) in 47 patients with PPS and 12 healthy

controls, using high density surface EMG. At baseline, all patients had symptomatic quadriceps dysfunction, evidenced by transmission defects on single-fibre EMG. *Results:* MU size and strength declined significantly by 20% and 15%, respectively, in patients with PPS. Those with the largest initial MU sizes exhibited the greatest losses of mean MU size (27%) and proportional decreases in quadriceps strength (23%). Initial strength, change in LOI and change in RMS amplitude together explained 35% of the variability in strength changes in patients. MU size of controls did not change, although they lost 29% strength. *Conclusion:* MU size and strength declined concomitantly in a homogeneous cohort of patients with PPS and quadriceps dysfunction. *Significance:* This long term follow-up study provides evidence that size diminution of enlarged MUs combined with a reduced number of active MUs contributes to the gradual strength decline in PPS.

SL28

BRAIN VOLUME STUDIES IN POST-POLIOMYELITIS SYNDROME PATIENTS

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Generalized fatigue is a common and disabling symptom of post-poliomyelitis syndrome (PPS). Fatigue in PPS has also been associated with cognitive difficulties such as reduced concentration and memory. Even though fatigue is a well-known symptom of PPS, the presence of objective cognitive difficulties in PPS is unclear. Acute paralytic polio involves not only the motor unit, but also produces encephalitis. It is possible that early brain inflammation in individuals with previous polio may produce permanent neuronal injury with brain atrophy. This injury could produce certain symptoms such as fatigue and cognitive difficulties. In other neurological disorders such as multiple sclerosis (MS), brain atrophy is a well-known consequence of the disease and has been associated with fatigue and cognitive dysfunction. We have completed a cross-sectional study aimed at evaluating brain volume in PPS patients. We also assessed the potential relationship of brain volume in PPS patients with fatigue. Normalized brain volume (NBV) was assessed with magnetic resonance imaging (MRI) and the automated program Structured Image Evaluation, using Normalization, of Atrophy method (SIENAX). Because this measurement includes primarily hemispheric volume, it is possible that regional brain atrophy such as in the brainstem may not be recognized. Fatigue was assessed with the Fatigue Severity Scale (FSS). Technically adequate scans were available for 42 PPS patients, 27 normal controls without neurological disease, and 49 MS patients. MS patients were included in our study as a positive control population. We found no significant reduction in NBV in PPS patients, but confirmed a significant reduction of NBV in MS patients. We did not find an association of NBV with fatigue in PPS patients. This presentation will review 1) nervous system involvement of acute paralytic polio and its potential association with clinical symptoms based on completed studies in PPS and other neurological disorders, 2) the results of our recently completed study of brain volume in PPS and MS patients, and 3) the implications of our results for PPS and future research in this area.

SL29

ORTHOPEDIC SURGERY IN POST-POLIO SYNDROME

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What is different in patients with Post-Polio Syndrome (PPS) compared to the «standard» orthopedic patient? Which are the

challenges we have to deal with? Which are the considerations we have to make while analyzing an orthopedic problem in patient with PPS, and which factors have influence on the decision making of a treatment plan? Some issues:

- patient expectation
- affected/non-affected side
- muscle weakness/paralysis
- bone quality – bone/joint size
- multiple previous treatments, not always successful.

Based on several clinical cases we will discuss the above mentioned items.

SL30

ORTHOPAEDIC SURGERY IN YOUNG POLIO SURVIVORS

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The orthopaedic surgery in young polio survivors is a challenge, because at this presenting age the deformities are very resistant and severe. Usually female patients, mostly belonging to the middle and lower socio-economic class families having more than two children. These polio victimised children are neglected by their parents in underdeveloped countries. When the victim reaches the marital age, parents realise the importance of treatment and surgery. That is when they come to us for improving deformity of the polio victimised patients. This, the very fact motivated me to undertake treatment and perform various surgeries on these patients, totally free of any professional charges. Till date, I have operated upon 5000 patients with various deformities in polio victims. Here in this presentation I will show my work on various cases of deformities involving Ankle & Foot, Hip & Knee, Length discrepancy with deformity, etc. I will be providing you with a protocol (Algorithm) for the step by step evaluation of patients, a treatment protocol and various surgeries for each deformity and appropriate rehabilitation. Algorithm pamphlets for treating Foot, Knee and Hip deformities will be made available. I personally feel that well planned surgery for such victims will definitely make polio victims totally independent and helpful to the society. By and large it is my observation that polio patients usually are intelligent, hardworking and want to remain independent. It is our duty to evaluate each case properly, plan the treatment and perform various surgical procedures and provide appropriate rehabilitation, so that young polio survivors can live in the society with proper repute and are never considered as disabled.

SL31

ANESTHESIOLOGY: A RISK IN POST-POLIO SYNDROME?

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Acute paralytic polio affects motor neurons, but may also affect neurons in central parts of the brain as the medulla oblongata and formatio reticularis, including centers for regulation of sleep and respiration. The affected neurons may fully recover, survive with some degree of malfunction or be lost for good. This has consequences in relation to general anaesthesia. Anaesthesia comprises of three components: relieving pain, inducing sleep and preventing muscle movement. These effects are brought about by inducing drugs that block chemical reactions in neurons. The magnitude of this blocking depends on the number of drug molecules in relation to the number of normal neurons. In a situation with less neurons or neurons with a suboptimal function, a lesser dose of medicine is required to reach the desirable effect – or put in other words: a normal dose may induce too much of an effect. Neuron lesions brought about by polio vary from subject to subject. It is therefore impossible precisely to predict who is at risk of an overdose of drugs, and who is not. The general rule must then be that any polio patient should start out with a small dose of medicine, adding more until the desired effect is

achieved. When polio survivors are having an operation it is also important to address of several other issues: 1) deformities of the neck may make intubation difficult, 2) deformities may cause the risk of compression ulcers and damage on nerves while situated on the operation table, 3) muscle mass may be replaced by fat, which result in a lesser volume of blood in spite of a normal blood count. As a result distribution of medicine throughout the body may be altered and the risk of blood loss may be underestimated. 4) paresis in the throat and vocal cords may hinder respiration or cause aspiration, 5) a greater risk of urinary retention, and 6) drop in temperature because of cold intolerance. Once these issues are addressed correctly, anaesthesia may be carried out safely in PPS. *Summary and key points:* Polio survivors are safely anaesthetised as long as drugs initially are given at small doses and subsequently adjusted, and attention is payed to possible impairments that can bring about complications.

SL32

TWENTY YEARS OF ORTHOTIC ADVENTURES IN POLIO: AN IRISH PERSPECTIVE

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The polio virus in Ireland affected thousands of children in the 1940's and 1950's. For many this resulted in permanent paralysis of the lower limbs with varying severity. These children grew into adulthood and have lived extremely full lives and contributed extensively to society. This presentation describes the orthotic treatment available for polio survivors in Ireland, from experiences over the last twenty years. Orthotic treatments have evolved due to advances in technology and materials in recent years. The challenges encountered in fitting and manufacturing orthoses for this group of patients are diverse and the importance of biomechanical principles combined with the individual's needs determine the optimum outcome.

SL33

STANCE-CONTROL ORTHOSES IN POLIO

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Stance-control orthoses (SCO) have knee joints that provide knee stability during stance by locking, and allow knee flexion by remaining free during swing. A SCO results in a more natural gait, that should be less energy consuming compared with a locked knee-ankle-foot orthosis (KAFO), since compensations to bring a stiff leg forward are not needed. Besides improved walking efficiency, overuse complaints due to necessary compensations for walking with a stiff leg may be avoided. Another advantage of a SCO is the better cosmetics of knee flexion in swing. After the first SCO became commercially available in the mid-nineties of the previous century, more SC-joints have been brought to the market. The various types of SC-joints are operated mechanically by knee or ankle movement or electronically by foot switches or accelerometers. Technically, the denominator 'stance-control' is incorrect, since several types of SC-joints are controlled in swing. The latest developments are microprocessor controlled SC-joints, that can vary their resistance to allow an even more natural gait and to adapt to specific locomotory tasks such as descending stairs. It is not simply the rule that the more active ambulatory patients qualify for a SCO. For severely affected individuals, with paresis in both legs, who cannot compensate for walking with a stiff leg when using a locked-KAFO, a SCO may be the only option to provide walking stability despite limited walking ability; provided that the patient meets the requirements that have to be met to apply the joint. Walking with a SCO requires automating correct operation of the joint. This sometimes results in slowing of

walking, and increase in energy cost compared to a locked-KAFO. Therefore, a SCO is certainly not always better than a locked-KAFO. In general, walking classes by physical therapists are required to learn to walk with a SCO. The selection of the SC-joint is done by matching the individual gait and preferences to the product properties of the different types of SC-joints. When more SC-joints can be applied, it comes down to preference and experience and of the providing orthotist and the patient, as long as comparative studies remain lacking.

SL34

ORTHOTICS IN DEVELOPING COUNTRIES

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The Orthopedic Training Centre was founded by a Dutch missionary called Br. Tarcisius de Ruyter (SVD) in May 1961. He was sent to Ghana to take care of the footwear needs of his fellow SVD confreres. In Ghana he saw many children with post-polio paralysis and decided to help them. That was the beginning of the OTC at Nsawam-Ghana. He attended different courses to enable him make walking aids (orthoses) to support these children. After his studies, he started to work with some young men of the village. He realized the need for a surgeon to release the many joint contractures due to crawling and sitting for a long time. At present there are two hospitals: (St Anthony's Hospital at Dzodze and St. John of God Hospital at Duayaw Nkwanta) performing different types of surgeries for such children. A Dutch Orthopedic Surgeon (Dr. Rompa) also visits these two hospitals two times each year to help with the surgery program. There is an out-reach program ("trekking") which makes it possible for the centre to travel out to all the regions of the country. This has been of tremendous help for those who cannot afford to travel to Nsawam for treatment. In the past, post-polio cases made up about 80% of the annual patients turnover. However the last 15 years saw a decline in the number of new post-polio cases seen at the centre or on trek. This was due to the polio immunization program started by the Ghana Government over the years. These immunization programs are very successful and are helping to create a polio free society in Ghana. *Challenges:* Even though the OTC covers all the ten regions of Ghana there are parts of the country the trekking team cannot visit due to little or no resources to support the team. *Future Plans to Improve:* The centre will like to strengthen its partnership with other donors and funding agencies to enable the trekking team reach many with post-polio paralysis and to continue to make walking aids to support many with post-polio paralysis.

SL35

POST-POLIO PATIENTS IN NORWAY; PAST AND PRESENT REHABILITATION

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Historically, polio patients in Norway received rehabilitation after the acute phase and until the condition stabilized. The criterion for successful rehabilitation was that the patient returned to society without serious consideration to their polio. Thereafter, most patients were left to themselves, until eventual late effects of polio occurred. Thus, rehabilitation for polio patients had low priority. In the 1990s, the pos-polio syndrome increased, and thereby also the attention. Rehabilitation services were built up again, also at Sunnaas Rehabilitation hospital, that has nation-wide services. The polio sequelae were often complex and necessitated the organization of a specific post-polio service within the specialist healthcare. Thus, Sunnaas Rehabilitation Hospital has offered interdisciplinary evaluations and treatment to post-polio patients since 1990, first group-based with

1–2 week duration, with a primary focus on evaluations, exchange of experiences and coping. Then, later individualized programs with focus on adaptation of activities and participation in home and community. During such a program, patients meet with an interdisciplinary team. Different laboratories are used to evaluate the gait, urodynamic and physiological conditions when needed. The prosthetics works with the team to evaluate the need of orthopedic aids. Referral to community based health care for home adaption, fall preventions and overall energy conservation are important issues to consider during the stay. Most of the polio population in Norway is older, with new demands on the health care system still unknown, which has initiated a new nation-wide survey among the polio population. New polio patient among immigrants are relatively few in Norway, but are increasing in number. Many of them have had little access to rehabilitation services, and therefore live in challenging situations. Thus, the need for rehabilitation services for polio patients will continue also in Norway for many years to come, and also the need for individualized type of such services for the oldest population and the new polio patients among the immigrants.

SL36

WHAT CAN WE LEARN FROM EACH OTHERS PRACTICES?

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The treatment of post-polio syndrome (PPS) is currently not well defined yet and certainly requires a multidisciplinary approach. However, we believe that first we should define the proper diagnosis in order to have the opportunity of a useful treatment. We consider this the most important and crucial step. Polio survivors who complain about new clinical symptoms are submitted to a careful clinical examination that cannot leave off the neurophysiological analysis. So a spinal stenosis can be responsible for pain, weakness and urinary disorders, as well as focal compression of one or more peripheral nerves can be the cause of muscle atrophy and consequent loss of strength, pain and loss of function. Electroneurography and evoked potentials, taking in account of the neurogenic changes due to polio, are able to distinguish these different conditions. Polio survivors also have a risk of developing other diseases sharing symptoms with PPS like myasthenia gravis, inflammatory myopathies, neuropathies and motor neuron disease. Once the diagnosis is done, many treatments can be applied, e.g. muscle strengthening exercises for muscle weakness; tecar therapy,

TENS and ultrasound therapy for pain relief, cycloergometer and endurance exercises for fatigue. Urological problems, like urge incontinence, at least in earlier stages are usually treated with both drugs and rehabilitation programs. Sleep disorders involve mainly pharmacological interventions. We were promoters of a double-blind trial with high-dose immunoglobulins that was not definitely conclusive about the efficacy of such immunomodulatory therapy. However, these partial results allow us to figure out a future on the etiological treatment of this disease.

SL37

BREAKING THE SILENCE – COPING WITH POLIO IN A THIRD WORLD COUNTRY

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In a Third World Country, Polio is “mystifying”, some regard it as a “curse”. “Who sinned in order for this person to become a polio victim?”, they ask, puzzled about it. In many cases the mother is to blame for a child’s disability. “We man as we are, do not bear disabled children”, they boast around over a drink. People go to the witchdoctors or prophets for consultations why a child has polio in a family. Coping with Polio in a Third World Country is very difficult.

- In general, children with Polio are segregated upon to attend school.
- They are segregated in getting some mobility assistive devices, such as wheelchairs, calipers, crutches, surgical boots, etc. The suppliers of such devices are very few and in some cases they are not there. In addition these mobility assistive devices are very expensive, out of reach of the majority of the Polio victims.
- Corrective surgery is for just a ‘chosen’ few, Polio victims.
- Public transport is a nightmare for the people with Polio. One cannot access the transport itself. And the transport itself is not adjusted to suit the Polio victims.
- Assessing to a health institution at times is very difficult, or not possible due to the unfriendly transport systems and the absence of the mobility assistive devices.
- Assessing public buildings remains as a “bone to chew” to the Polio victims, since a number of them are not accessible to them.
- The rural folks with Polio in a Third World Country finds its difficult to fetch some water from the deep wells and, to fetch some firewood from the forests.
- Economically, a very few Polio cases earn a good standard of living in a Third World Country. They do not have the jobs.
- For those Polio victims in some decent love relationships, about to get married, (just like any one else), parents and siblings disapprove such relationships.
- Laws have been legislated, but they are not abided by.

Yes, who shall break this silence and de-mystify Polio in order for the Polio victims and survivors to enjoy life in a Third World Country? Is it the European Polio Union, the Academy Medical Center of Amsterdam, the Danish Society of Polio & Accident Victims or the Karolinska Institutet.

FREE PRESENTATIONS (FP1–FP29)

FP1

BLOOD LIPIDS LOW IN PATIENTS WITH POST-POLIO SYNDROME**Eva Melin, MD¹, Thomas Kahan², MD, PhD, Kristian Borg, MD, PhD¹**¹Div of Rehabilitation Medicine and ²Div of Cardiovascular Medicine, Danderyd Hospital, Karolinska Institutet, Stockholm, Sweden

Introduction: The post-polio syndrome (PPS) is a condition occurring in people who previously had poliomyelitis. The impaired mobility in PPS patients might increase their risk of cardiovascular disease. Elevated levels of inflammatory markers in cerebrospinal fluid and blood in PPS suggest a persisting inflammatory process. Inflammation and dyslipidaemia may also play an important role in the development of atherosclerotic complications. **Methods:** We recruited 89 consecutive PPS patients (53 women, mean age 65 years) from our Post-Polio Outpatient Clinic. Serum lipid data was compared to two published studies, providing reference values. NORIP (Scand J Clin Lab Invest 2004; 64:271-84) provides data for total cholesterol, low and high density lipoproteins (LDL, HDL) in 3036 healthy Nordic individuals. The Jungner study (Clin Chem 1998; 44:1641-9) provides results for total cholesterol and triglycerides from general health screening in Sweden in 14,7576 subjects, however with no information on concomitant disease or the use of medication. **Results:** With all patients included, total cholesterol, LDL, HDL, and triglyceride levels were 5.72, 3.63, 1.47 and 1.38 mmol/l, respectively. Total cholesterol was lower than reference values (Jungner 6.36 mmol/l, $p < 0.001$; NORIP 5.92 mmol/l, $p = 0.09$), LDL was similar to reference values (NORIP 3.64 mmol/l, $p = 0.9$), HDL was lower than reference values (NORIP 1.68 mmol/l, $p < 0.001$), and triglycerides were lower than reference values (Jungner 1.55 mmol/l, $p = 0.05$; NORIP 1.54 mmol/l, $p = 0.05$). When only patients without lipid lowering medication were included, total cholesterol, LDL, HDL, and triglycerides were 5.94, 3.82, 1.52, and 1.31 mmol/l respectively. Total cholesterol and LDL were then similar to reference values (NORIP, 5.91 mmol/l, $p = 0.81$, NORIP, 3.64 mmol/l, $p = 0.10$ respectively), whereas HDL and triglycerides remained lower than reference values (NORIP, 1.69 mmol/l, $p = 0.001$, NORIP, 1.54 mmol/l, $p = 0.003$, respectively). **Conclusion:** Compared to a reference population, PPS patients in Sweden appear to have lower levels of total and HDL cholesterol, and triglycerides, whereas LDL cholesterol is normal. Hence, the inflammatory process in PPS does not seem to be associated with increased lipid values.

FP2

QUANTITATIVE MUSCLE ULTRASOUND AND QUADRICEPS STRENGTH IN PATIENTS WITH POST-POLIO SYNDROME**Alice Bickerstaffe, MD¹, Anita Beelen, PhD¹, Machiel Zwarts, MD, PhD², Frans Nollet, MD, PhD¹, Hans van Dijk, PhD²**¹Department of Rehabilitation, AMC, Amsterdam, The Netherlands, ²Epilepsy Centre Kempenhaeghe, Heeze, The Netherlands

Introduction: We investigated whether muscle ultrasound can distinguish muscles affected by post-polio syndrome (PPS) from healthy muscles; and whether severity of ultrasound abnormalities is associated with muscle strength. **Methods:** Echo intensity, muscle thickness, and isometric strength of the quadriceps muscles were measured in 48 patients with PPS and 12 healthy controls. **Results:** Patients with PPS had significantly higher echo intensity and lower muscle thickness than healthy controls. In patients, both echo intensity and muscle thickness were independently associated with muscle strength. A combined measure of echo intensity and muscle thickness was more strongly related to muscle strength than either parameter alone. **Discussion:** Quantitative ultrasound distinguishes healthy muscles from those affected by PPS and

measures of muscle quality and quantity are associated with muscle strength. Hence, ultrasound could be a useful tool for assessing disease severity and monitoring changes resulting from disease progression or clinical intervention in patients with PPS.

FP3

THE NEUROLOGICAL FATIGUE INDEX FOR POST-POLIO SYNDROME (NFI-PP): A PATIENT DERIVED, RASCH-STANDARD SCALE**Carolyn Young, MD, FRCP¹, Anne-Marie Quincey, BSc¹, Samantha Wong, MPhil¹, Alan Tennant, BA, PhD, MD (honoris causa)²**¹Walton Centre NHS Foundation Trust, Liverpool, ²University of Leeds, Leeds, UK

Introduction: Post-Polio Syndrome (PPS) is characterised by the onset of fatigue, new muscle weakness, and other symptoms. However, to date there is no patient self report measure of fatigue validated in PPS. We aimed to develop one based on patient experience and meeting rigorous psychometric standards. **Methods:** Qualitative interviews on fatigue were undertaken with 45 patients diagnosed with PPS according to published criteria. From these transcripts, 62 statements were used to construct a draft questionnaire. This was sent to people with PPS, along with comparative questionnaires, including the Fatigue Severity Scale (FSS). **Results:** 271/315 questionnaire packs (85%) were returned. Exploratory Factor Analysis of data from the 62 items identified a two-factor solution (RMSEA 0.058) comprising physical and mental fatigue. All items were retained as a potential two-domain scale. For the physical domain, various items were removed due to misfit to the Rasch model, for DIF, and for local dependency. A final 20 item scale showed good fit (Chi Square $p = 0.189$), strict unidimensionality (t -test 5.17%: CI 2.6-7.8), and reliability of 0.91. For the mental scale a final 7 item scale showed excellent fit (Chi Square $p = 0.917$), strict unidimensionality (t -test 5.2%: CI 3.0-8.2), and reliability of 0.89. A total score was found to satisfy Rasch model expectations after making two testlets to accommodate local dependency within the physical and mental item sets. Thus a total 27 item scale showed good fit (Chi Square $p = 0.151$), strict unidimensionality (t -test 0.4%: CI 3.0-8.2) and a reliability of 0.94. With the latent estimate transformed to a 0-100 scale, the mean score was 51.45 (SD 9.7) and none of the respondents were at either the floor or ceiling of the scale. Correlations with the FSS and a VAS scale for fatigue were 0.60 and 0.56 respectively. **Conclusion:** A 27 item patient-derived Neurological Fatigue Index for post-polio syndrome has demonstrated excellent reliability, appropriate concurrent validity, and satisfies the rigorous standards of the Rasch measurement model. It offers physical and mental domains, as well as a total score. Given this, a raw-score to interval scale transformation is available for parametric applications, and the calculation of change scores.

FP4

DEVELOPMENT AND VALIDATION OF NEUROLOGICAL COPING INDEX – POST-POLIO SYNDROME (NCI-PPS)**Kristijonas Milinis, MBChB¹, Alan Tennant, BA, PhD², Shruti Kaushal, BSc³, Charlotte Taylor, BSc³, Carolyn Young, MBChB, MD³**¹University of Liverpool, Liverpool, ²University of Leeds, Leeds, ³The Walton Centre NHS Foundation Trust, Liverpool, UK

Introduction: Post-polio syndrome (PPS) is characterised by worsening weakness, pain and fatigue, following a period of prolonged stability. These symptoms cause detrimental effects on physical and

psychosocial functioning, requiring the individual to utilise coping strategies to face new challenges and address stress. Previous research suggests that the strategies used by people with PPS to cope with the condition reflect their unique experience of polio and may therefore not be adequately captured by generic coping scales. *Objective:* To develop and validate a coping scale for people with post-polio syndrome, meeting rigorous modern psychometric standards. *Methods:* Forty-five people with PPS were interviewed to identify themes and to derive potential items. After cognitive debriefing, the coping questionnaire was posted to 319 patients. A subgroup of patients was invited to complete the same questionnaire after 2–4 weeks. *Results:* A preliminary 81-item scale with 4 response categories was derived from the qualitative interviews. 193 (61.4%) respondents completed the questionnaire. The data was subjected to Exploratory Factor Analysis and a Rasch analysis which produced a 15-item scale. Thematic analysis of the discarded items indicated a common theme of self-efficacy. The final scale, Neurological Coping Index – Post Polio Syndrome (NCI-PPS), after collapsing response categories to 3, showed good fit to the Rasch model (Chi Square 39.1 (df 30) $p=0.12$), strict unidimensionality (t-tests 4.17% CI: 1.1–7.2), and a Cronbach's alpha of 0.80. Retest analysis of the scale completed by 52 patients showed good short term reliability ($r=0.67$, $p<0.001$). *Conclusion:* A 15-item NCI-PPS scale has been designed to measure coping in PPS, the component items are based on the lived experiences of people with PPS. Rasch analysis confirmed sound modern psychometric properties of the scale. The NCI-PPS is the first in a series of patient-derived and Rasch-based scales for the measurement of coping in chronic neurological conditions.

FP5

POLIO- & POST-POLIO SYNDROME NEED ATTENTION REGARDING PALLIATIVE CARE IN A RURAL (DESERT) COMMUNITY OF PAKISTAN

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Taluka Khipro Sindh, Pakistan, Sindh United (n) Developmental Educational Rural Society and RCK-Sunders, National Pakistan Polio Plus Committee

Introduction: Polio is a major cause of physical disability around the world; acute polio may sometimes be lethal. Post-polio syndrome is a health issue among polio survivors. In the rural (desert) community of the Taluka Khipro in the Sanghar district of the province Sindh, Pakistan, there are polio survivors who have health complaints and clinical features of post-polio syndrome. *Aim:* To analyse the quality of polio registrations and the need of rehabilitation and palliative care among polio survivors with complaints of post-polio syndrome. *Materials & Methods:* Enquiries in the community by asking and discussing with inhabitants during the advocacy and awareness sessions of the polio vaccination campaigns. All identified cases were investigated with questionnaires and clinically evaluated to confirm the diagnosis of post-polio syndrome and to assess the need for palliative care. Polio survivors were checked if they were registered. *Results:* 110 polio cases were identified in the community. Forty-seven of them, all of older age, had not been registered as polio disabled in the community. Sixty (54%) of the 110 polio cases had symptoms of post-polio syndrome and were in need of special attention regarding palliative care. Of these 60 cases, 33 (55%) needed proper rehabilitation, 11 (18.3%) needed care for complaints of pain and fatigue, 2 (3.3%) needed care for chronic constipation, 7 (11.6%) for depression, and 7 (11.6%) needed proper ventilator care. *Conclusion:* The polio survivors living in the rural (desert) community Pakistan face many health care issues with special need of rehabilitation, psychological support, and palliative care.

FP6

DISCRIMINATION OF POLIO SURVIVORS IN INDIA

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Recently India celebrated its 3-year anniversary of being a polio free nation. However it is important to not be ignorant about the sufferings of persons who have been affected by polio or polio survivors in India. Polio is often thought of as synonymous with paralysis and disability. It is also known as one of the leading causes of physical disability in India. Persons with disabilities are one of the most oppressed, marginalised and stigmatized groups in the Indian society. In the Indian context; cultural and religious beliefs are so deeply imbedded that they have an effect on the attitudes of the society at large. Disability is often viewed as a form of karma where one is paying for his/her misdeeds committed in the previous lives (Ghai, 2002). This leads to further societal prejudices which deny them of their basic rights and entitlements. Moreover the social and physical environment is often disabling which leads to lack of access to healthcare, education and livelihood. So far, majority of the studies have focused on the efforts of the polio eradication campaign while there are not many studies that highlight the status of the polio survivors. This paper aims to understand discrimination faced by polio survivors in the areas of education, livelihood, health and social inclusion with theories that underpin discrimination and stigma. This paper would also try to understand how different aspects of life such as gender, religion, caste and economic status have a further effect on the discrimination of polio survivors within the Indian context which leads to further ostracisation of the polio survivors. Also the current paper would aim to provide some suggestions on possible interventions that could be taken by the society at large to prevent discrimination of polio survivors.

FP7

AFTERTHOUGHT: LIVING WITH POLIO IN THE POST-ELIMINATION ERA

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Introduction: One of Public Health's greatest feats is the elimination of polio from a majority of the world. But has polio really disappeared? About 25–50% of polio patients are expected to experience post-polio syndrome (PPS), characterized by muscular weakness, atrophy, pain, and fatigue. It is estimated that there are about 300,000 individuals living with polio in Gujarat, India today. Addressing the needs of this population can improve their quality of life and set a precedent for disabilities advocacy. Based in Gujarat, I aimed to understand the experiences of individuals with polio, to assess the perceptions of medical and lay individuals about PPS management, to evaluate social support for people with polio, and to increase awareness of PPS. *Methods:* This is a qualitative study in which I conducted semi-structured interviews with individuals with polio, medical practitioners, and lay people to assess their perceptions of disability, polio, and PPS. There were no exclusion criteria. The questions were altered to reflect the individual being interviewed. The data were compiled from 50 interviews. The interviews were conducted in Ahmadabad, Bhavnagar, Surat, and Vadodara. *Conclusions:* There is very little awareness of PPS among polio-affected people, medical practitioners, and lay people in central Gujarat. Moreover, there is a dire necessity to improve infrastructural accessibility to basic institutions like hospitals, police stations, and public markets. Finally, societal marginalization and lack of successful administration of governmental policies creates additional difficulties for those affected. *Discussion:* The status of polio as an eliminated illness creates dichotomies in patients' understanding of and reaction to their post-polio syndrome illness experience. Labeling an illness as "eradicated" fuels the rarefaction of its chronic and long term effects and contributes to professional and personal misconceptions of that illness. Social support structures, including peer support groups, are vital in combating these effects. Improving infrastructural accessibility can improve the overall health of people with physical differences by improving access to resources

and self acceptance. By understanding how patients find and utilize these resources, community organizations can open new avenues for sustainable disease management.

FP8

THE RELATIONSHIP BETWEEN THE POLIO ENDEMIC AND EXTREME POVERTY IN THE NORTHERN PART OF NIGERIA

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Between 1988 and 2013, polio cases have been successfully reduced by more than 99% across the globe declining from 300,000 per year to just 300 cases. Nigeria is one of the 3 countries where poliomyelitis is still endemic with a record of 122 cases in 2012, which was about half of the global estimates of polio. States in the northern part of the country are the main source of polio infections thereby making these states where much of polio victims are located. The study analyzes the history of the polio endemic in Nigeria and the progress the Nigerian Government and others have made in eradicating the endemic as soon as possible; further to this, the study analyzes the extreme poverty profile of the country based on living below the World Bank \$1.25 extreme poverty threshold. This study investigates the relationship between being polio victims and living in extreme poverty in the northern part of Nigeria. The study focuses on adult polio victims aged 15–64 and uses living below the World Bank \$1.25 extreme poverty threshold as yardstick for measuring extreme poverty among them. 40 polio victims each were surveyed in Jigawa, Katsina, and Kano States (northern part of Nigeria), and the results of the survey revealed that 97%, 95%, and 90% of polio victims surveyed in Jigawa, Katsina, and Kano States were living below the World Bank \$1.25 extreme poverty threshold thereby confirming a relationship between being polio victims and living in extreme poverty in the northern part of Nigeria. The study finally proffers some suggestions as to how to totally eradicate the polio endemic and how to help the polio victims in the country out of the extreme poverty trap.

FP9

SELF MANAGEMENT OF THE LATE EFFECTS OF POLIO – SEEKING GOVERNMENT AND PRIVATE FUNDING SUPPORT: THE AUSTRALIAN EXPERIENCE

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For Australia's Polio Survivors the provision of specific health and disability services by the state and federal governments ranges from insufficient to non-existent across the country. Polio Australia has actively sought to raise awareness of the late effects of polio (LEoP) and how to manage it with health professionals, governments and polio survivors who often make poor choices when managing their condition because of a low level of specific health literacy about how to manage their condition. Over the last 6 years Polio Australia has developed; websites, a National Register, health literacy materials, and specific programs as a service to Australians living with the LEoP to help them self manage their condition. The provision of such services to a wider group of polio survivors is greatly hampered by a lack of public and private funding. Over the last 6 years Polio Australia has developed a range of sophisticated advocacy methods to raise awareness amongst government decision makers of the specific needs of polio survivors and the need to fund specific programs. This has included; the appointment of Federal Parliamentary Patrons, the establishment of Parliamentary Friends of Polio Survivors, lobbying meetings with key government decision makers, the holding of a Parliamentary Inquiry into the needs of polio survivors and "We're Still Here!" campaigns where up

to 60 polio survivors and their supporters have descended on the Australian Federal Parliament. Due to the uncertainty of government funding over time, we have also developed a wide range of private funding sources. In recent years Polio Australia has begun to tap into; foundation funding, private company sponsorships, developing a partnership with Rotary International, individual donations and bequests, and an annual "Walk with Me" activity for polio survivors, their family and friends. All these strategies have been highly successful in raising awareness, at the highest levels in Australia, of the needs of people with the LEoP. Our current challenge is to change the flow of our various funding sources from a trickle to a flood! Only in that way will we be able to reach the vast number of Australian polio survivors whose LEoP condition is not being managed properly as they age.

FP10

PAINTING THE SAME PICTURE CAN PROVIDE BETTER CLINICAL OUTCOMES

Hilary Boone

Polio Survivors Network, Lincoln, England

The most reported issue to Polio Survivors Network is the number of months before reported new medical symptoms result in a diagnosis. My prior polio was not in the equation for 7 years. The UK free National Health Service allocates times for appointments from 10 minutes up. This restricts the time for history taking, physical assessment, organising further tests, discussing the next step. Effective communication between patient and practitioner will result in better outcomes. The first two minutes defined as 'Golden' leads to our recommending patients respond to their professionals greeting with 'Thank you for seeing me about [define major issue], e.g. 'the new pain and weakness I have been experiencing in my arms for 6 months'. Many polio survivors report closed questioning, e.g. "Can you do x?" Unfortunately the "Yes or No" answer is only providing a few brush strokes. Open questioning, e.g. "How do you do x?" will allow polio survivors to tell it like it really is and paint a better picture. Physical assessment of weakness usually takes the form of Manual Muscle Testing. In 1997 a medical report stated 'On neurological examination of the legs power at the left hip, and knee and ankle was normal'. My weakest polio limb was my left leg. No health professional would report what he did not believe to be true. I had passed a medical for the Police in 1969 but was unable to rise from a squat or run. The reliability and validity of single action MMT must be faulty, confirmed Dr. Halstead/Dr. Maynard 2000. Patient endurance, both repetitive and sustaining, and the ability of a muscle to perform as part of a pattern of movement is often not being tested. Polio Survivors and others with muscles that weaken after single testing are still reporting limb, respiratory and swallowing muscles being over graded. Encouraging patients to self-assess and provide more pertinent information will support more effective consultations e.g. I can no longer beat eggs with wrist rotation changed my 19 years of recorded 'no weakness found' to 'very weak supinators'.

FP11

ILLNESS EXPERIENCES OF PEOPLE WITH POST-POLIO SYNDROME

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Background: Post-polio syndrome (PPS) has been increasingly studied from a medical perspective over the last decade. In literature most of the studies have focused on aspects of the physical disability, treatments or interventions or quantitative measured quality of life. Although these studies provide important knowledge, they do not give insight in the interrelation of the social context, emotional adaptation or change of individuals perspectives during the process

of PPS. *Aim:* The aim of our study was to gain an interpretative understanding of the subjective impact of PPS. This can help professionals to better understand the needs of these patients and to improve the care based on these needs. *Methods:* A qualitative study was executed, using in-depth, narrative interviews with 16 PPS patients. Beside the interviews, a homogenous focus group was held with 5 patients. The data were audio taped, fully transcribed and analysed thematically. *Results:* In the presentation attention will be paid on the different illness experiences of patients with PPS. These results will be linked to relevant theories about illness experiences. *Conclusion:* This qualitative study makes it possible to arrive at a greater understanding of the illness experiences of patients with PPS.

FP12

LEARNING FROM THE PAST: POLIO SURVIVORS EXPERIENCES PRIOR TO THE CREATION OF THE BRITISH NATIONAL HEALTH SERVICE

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Background: Despite the development of a vaccine polio has still not been eradicated in some countries. Whilst the UK remains polio free there were serious outbreaks of polio prior to the formation of a free National Health Service (NHS) in 1948. There are cultural and social phenomena that are specific to the UK that may influence the experience of living with such a disability. Currently polio survivors are now experiencing a wide range of health difficulties which are referred to as post-polio syndrome (PPS). *Method:* Our research explored experiences of people living with polio and their treatment, prior to the formation of the NHS who are now ageing with a long term disability. Thirteen individual in-depth interviews with polio survivors who contracted polio prior to 1948 were analysed. All interviews were carried out by a polio survivor and analyzed using the constant comparison approach. *Findings:* Many of the participants' stories highlighted polio survivors' isolation from families, poor care once in hospital, treatment carried out without consultation, a school system that excluded them and devoted families. Stories often focused on there being 'no concessions'. *Conclusion and Implications for Practice:* Our research is of importance to health care professionals and polio survivors particularly in relation to the number of people ageing with polio. Their life experience may account for many aspects of their character including the formation of the so called polio personality, the coping strategies used and their occupations. It enables both polio survivors and health care professionals to understand how the past can relate to the present, current and future hopes and wishes as well as compliance with rehabilitation.

FP13

THE EFFECTS OF A HOME-BASED ARM ERGOMETRY EXERCISE PROGRAMME ON PHYSICAL FITNESS, FATIGUE AND ACTIVITY IN POLIO SURVIVORS; A RANDOMISED CONTROLLED TRIAL

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Introduction: Many polio survivors report significant barriers to physical activity and the prevalence of lifestyle related health risk factors

is high. Access to appropriate, accessible exercise programmes may enable polio survivors to avoid secondary disability and health problems. *Method:* The outcome of an 8-week, home-based arm ergometry aerobic exercise programme was investigated in a randomised controlled trial of 55 polio survivors. The Beaumont Hospital Medical Ethics (research) committee approved the protocol. The change in physical fitness was evaluated using a submaximal Six-Minute Arm Test (6-MAT) examining heart rate, rate of perceived exertion (RPE) and blood pressure. Fatigue, pain, mobility, activity and quality of life were assessed using the Fatigue Severity Scale, pain visual analogue scales, the Six-Minute Walking Test, the Physical Activity Scale for Individuals with a Physical Disability and the Short Form-36 respectively. In addition, compliance was assessed using exercise diaries and perceived benefit using a questionnaire. *Results:* Forty-two females and thirteen males participated, with 26 participants (male=5) allocated to the intervention and 29 (male=8) to the control group. The between group differences in heart rate and RPE during the 6-MAT at follow-up were not statistically significant ($p=0.15$, $p=0.08$). Blood pressure at follow-up was significantly lower in the intervention group ($p=0.04$). There were no significant differences between the groups in secondary outcome measures. Compliance with the programme was excellent. Participants perceived the programme to be of benefit. *Conclusion:* Blood pressure was better in the intervention group at follow-up, which suggested improved cardiovascular health. Although the changes in physical fitness and impairments related to the late-onset sequelae of polio were not significant the programme did allow otherwise inactive polio survivors to access aerobic exercise and experience the associated health benefits

FP14

EXERCISE THERAPY AND COGNITIVE BEHAVIOURAL THERAPY TO IMPROVE FATIGUE IN POST-POLIO SYNDROME: PRELIMINARY RESULTS OF A RANDOMIZED CONTROLLED TRIAL

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Introduction: Post-polio syndrome (PPS) is a complex of late onset neuromuscular symptoms with new muscle weakness and muscle fatigability as key symptoms. Main clinical complaints are severe fatigue, and deterioration in functional abilities and health-related quality of life. To reduce fatigue and improve functioning, two different rehabilitation interventions may be prescribed: (1) exercise therapy (ET) or (2) cognitive behavioural therapy (CBT). However, evidence on the effectiveness of both these interventions in patients with PPS is limited. *Aims:* To study the efficacy of ET and CBT (compared to usual care) on reducing fatigue and improving daily activities and quality of life in patients with PPS. *Methods:* We conducted a multi-centre, single-blinded, randomized-controlled trial (Dutch Trial Register NTR1371). A sample of 68 PPS patients with severe fatigue (a score on the Checklist Individual Strength-subscale fatigue (CIS20R-EF) ≥ 35) was recruited from 7 university hospitals and rehabilitation centres in the Netherlands. Participants were randomized to 1 of 3 groups: (1) 16 weeks ET + usual care, (2) 16 weeks CBT + usual care, (3) 16 weeks usual care. ET aimed at improving physical capacity consisted of home-based aerobic training on a cycle ergometer (three times weekly) and supervised group training with muscle strengthening and functional exercises (once a week). CBT was aimed at changing perpetuating factors for fatigue, using individualized treatment modules. The primary outcome was reduction in fatigue (CIS20R-EF score) immediately post-intervention (outcomes were also assessed at 3- and 6-months follow-up), analyzed with a mixed linear-regression model adjusted for baseline fatigue. *Results:* Preliminary results show that the CIS20R-EF score immediately after ET and CBT did not differ

from the CIS20R-EF score in the control group (mean differences -0.56 , 95% CI -5.70 to 4.57 , $p=0.83$ and 2.02 , 95% CI -2.84 to 6.87 , $p=0.41$, respectively). Also, at 3 and 6 months no favourable effects for ET or CBT were found. Three adverse events were reported in the ET group (joint pain of the knee and elbow, and trochanteric bursitis). *Conclusions:* These results suggest that fatigue in PPS cannot be relieved by exercise training or a cognitive behavioral intervention. Further analyses on the gathered data need to be finalized to determine the effects of both interventions on daily activities, quality of life and secondary outcomes.

FP15

IVIG TREATMENT IN POST-POLIO SYNDROME

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Forty patients were treated with IVIG 2 g/kg over 5 consecutive days. A second series of IVIG with the same dose was given following 6–9 months. The main complaints in post-polio patients are loss of muscle power, fatigue and pain. *Method:* 6 minutes walk test (6MWT), VAS scale and a questionnaire for fatigue were administered before first IVIG series, 6–9 months later, and 3–6 months after the second IVIG series. *Results:* Twelve patients refused to have the second series of IVIG: 3 due to side effects, 9 due to lack of effect. So, 28 patients were included in the final analysis. A significant increase in 6 MWT from $155 \text{ m} \pm 127$ to $228 \text{ m} \pm 143$ and $212 \text{ m} \pm 149$ were seen ($p<0,05$). A reduction in VAS scores was noted from 3.0 ± 2.7 to 1.5 ± 2.1 and 2.4 ± 2.6 ($p<0,05$). The scores from the fatigue questionnaire improved from 56 ± 11 to 51 ± 12 and 50 ± 13 ($p<0,05$). Generally the patients experienced a marked improvement of quality of life after the treatment.

FP16

RESTLESS LEG SYNDROME IN POLIOMYELITIS

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Objective: We aimed to evaluate the frequency and determinants of restless legs syndrome (RLS) in a patients with poliomyelitis (PM). *Methods:* A diagnosis of RLS was made according to the criteria of the International RLS Study Group, and severity was assessed by the RLS rating scale. Information on sex, age, age at onset, site of onset, disease duration, if patient presented post-polio syndrome (PPS) was obtained in a cohort of 43 PM patients. *Result:* Mean age of patients with PM was 55.3 ± 6.8 years. RLS was observed in 16 patients (37%). Restless legs symptoms was severe to very severe in 14 patients, moderate in 1 and mild in 1. RLS occurs more often in the affected (in 92% of patients) than in the less-affected leg. Restless leg rating scale was 28.6 point before treatment which reduced significantly to 7.8 point after dopaminergic agonist treatment ($p<0.001$). *Conclusion:* RLS occurs frequently in PM, and those affected should be identified and appropriately treated.

FP17

RELATIONSHIP BETWEEN PHYSICAL ACTIVITY, KNEE MUSCLE STRENGTH AND GAIT PERFORMANCE IN PERSONS WITH LATE EFFECTS OF POLIO

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Introduction: Physical activity is equally beneficial and improves quality of life for people with or without a disability, and can reduce impairments among people with a disability. Health status and personal factors are associated with physical activity in both disabled and non-disabled persons, but the evidence for predictors is inconclusive for persons with disabilities. In persons with late effects of polio, their impairments impact on activity, participation, life satisfaction and most likely the possibility to be physically active. To individualize health promotion programs for persons with late effects of polio we need to increase our understanding of the associations between physical activity, impairments and activity limitations. The aim of this study was to assess the relationship between physical activity, knee muscle strength, gait performance, age, sex and BMI in 77 persons with late effects of polio. *Main outcome measures:* Physical activity was described by the Physical Activity and Disability Survey (PADS), which measures physical activity in four subscales (exercise, leisure, household and work), and by a pedometer (steps per day). Isokinetic concentric knee extensor and flexor muscle strength was measured at $60^\circ/\text{s}$ in a Biodex dynamometer. Gait performance was assessed by Timed "Up and Go", comfortable gait speed, fast gait speed and 6-Minute Walk Test. *Results:* The PADS leisure subscale was significantly correlated with all knee muscle strength measurements ($p<0.01$) and two of the gait performance measures, comfortable gait speed and 6-minute Walk Test ($p<0.05$). The number of steps per day was significantly correlated with all knee muscle strength measurements and all gait performance tests ($p<0.01$). Knee muscle strength and gait performance explained up to 8% of the variance in the leisure subscale and 15% to 31% of the variance in the number of steps per day. *Conclusions:* Physical activity is associated with a diversity of factors and measurements of knee muscle strength and gait performance can only explain a small part of the ability to be physically active.

FP18

STANDARDIZATION OF QUANTITATIVE DATA OF GAIT CHARACTERISTICS OF POST-POLIOMYELITIS PATIENTS

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Objectives: To evaluate the differences in gait characteristics and gait symmetry of post-polio syndrome (PPS) patients ambulating with or without shoes and between subgroups walking with different walking aids and orthoses, study the correlation of these data with personal data, illness condition, physical health, frequency of using aids and orthotics and frequency of falls, and derive recommendations for standardization of reporting these data. *Method:* Twenty-six PPS subjects ambulated with their own walking devices. We calculated spatio-temporal parameters and symmetry indices (SI) of gait using a data acquired by a motion capture system. We compared inter-subject differences in gait pattern for PPS groups that differed by questionnaire-obtained data of demographics, physical activity, polio history, falls and walking aids. Additional inter-subject comparisons were performed between normal subjects ($n=16$), PPS patients walking with shoes with/without an ankle-foot-orthosis ($n=11$), PPS patients walking with knee-ankle-foot-orthosis ($n=5$), and PPS patients walking with a walker/crutches ($n=10$). We also compared intra-subject variability in PPS subjects who were able to repeat the trials barefoot. *Results:* Our main results show that subjects who reported participating in physical activity twice a week or more had significantly better step time and double support symmetry. Subjects who use walking aids on a daily basis had significantly higher gait cadence and shorter stride time. Also, subjects that do not require knee-ankle-foot orthoses and/or walking aids walked with a smaller base width and better symmetry in stance and swing durations than PPS subjects who require these aids. *Conclusions:* The gait pattern of PPS patients is related to numer-

ous intrinsic and extrinsic factors. Standardization of the reporting protocol of gait-related data of PPS patients is crucial for patient evaluation and treatment design.

FP19

BENEFITS OF A STANCE AND SWING CONTROL LONG LEG BRACE IN POLIO SURVIVORS

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Introduction: Polio survivors with weak quadriceps muscles walk unstable at a reduced speed and an increased walking effort. To overcome these gait problems, a knee-ankle-foot orthosis (KAFO) can be prescribed. While traditional KAFOs with locked knee joint allow for ambulation with a stiff orthotic leg, recent technical advances have provided a variety of stance control orthoses that enable the knee to freely flex during swing but are locked under weight bearing. A stance and swing control orthosis (SSCO) may allow for knee flexion under weight bearing, thereby offering the opportunity to walk in a way that feels very similar to natural movement. This pilot study evaluated the effect of a SSCO on gait biomechanics, walking effort and gait speed in two female polio survivors. **Methods:** Subjects enrolled in the study were provided with a carbon fibre-reinforced prepeg SSCO with hydraulic microprocessor-controlled knee joint (C-brace®, Otto Bock Healthcare). Participants were measured while walking with their own KAFO (locked) and at 12-weeks follow-up, walking with the C-brace®. In each condition, gait biomechanics were measured with 3D-gait analysis, and ambulant registration of gas-exchange during a 6-minute walk test determined walking effort and comfortable gait speed. Results Compared to the locked KAFO, in both patients, walking with the C-Brace increased knee flexion under weight bearing and knee extension during terminal stance. Concerning walking ability outcomes, in subject 1 walking effort was increased (+26%), while gait speed was reduced (-32%). Gait speed in subject 2 was also reduced (-9%), though at the gain of an 11% decrease in walking effort. **Discussion and conclusions:** The results of this pilot study indicate that a SSCO enhances gait performance by supporting knee flexion under weight bearing and knee extension during terminal stance. Furthermore, a SSCO may also reduce walking effort, although this was only seen in one subject. We speculate that the increased walking effort in subject 1 is partly related to suboptimal orthosis settings (ankle spring element too stiff). Besides, the weight of the orthosis may have increased walking effort by reducing comfortable gait speed. Future study is needed to extend our preliminary results.

FP20

COMPARING THE EFFECT OF A DORSAL-LEAF-SPRING AFO AND A SPRING-HINGED AFO ON GAIT CHARACTERISTICS IN PLANTARFLEXOR WEAKNESS – A PILOT STUDY

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Introduction: For polio patients with weak plantarflexors, a carbon-fibre ankle-foot orthosis (AFO) can be provided to improve stability by counteracting excessive ankle dorsiflexion and reduce walking energy cost (EC) by taking over ankle work. For this, two types of AFOs can be used: a dorsal-leaf-spring-AFO (DLS-AFO) or a spring-hinged-AFO (SH-AFO). The advantage of the SH-AFO is that stiffness and range-of-motion (ROM) can be adjusted indepen-

dently in plantar- and dorsiflexion direction, which is not possible in the DLS-AFO. However, the highest spring stiffness available for the SH-AFO is much lower than that available for the DLS-AFO. It is unknown how this will affect gait in flaccid paresis. In this pilot study we compared the effect of a DLS-AFO and a SH-AFO, both with various stiffness and ROM settings on gait biomechanics and EC in a polio survivor with plantarflexor weakness. **Methods:** One polio survivor (58 years) with unilateral plantarflexor weakness (MRC 3) participated. For this patient, a DLS-AFO with 5 carbon springs (stiffness range: 0.8–7.3Nm/deg) and a SH-AFO with NeuroSwing® hinge with 5 springs (stiffness range: 0.1–2.3Nm/deg) were custom-made. Gait biomechanics were assessed for 2x5 AFO conditions (k1–k5) and shoes-only. Subsequently, EC was assessed during a 6-minute walk test for 2x3 AFO conditions (compliant, moderate, stiff) and shoes-only. **Results:** The SH-AFO allowed on average $7\pm 1^\circ$ plantarflexion in loading response, while plantarflexion with the DLS-AFO reduced from 7° to 3° with increasing stiffness. All springs reduced ankle dorsiflexion ROM compared to shoes-only (17°). Dorsiflexion ROM reduced with increasing stiffness in both AFOs (k1-k5: SH-AFO $12-6^\circ$, DLS-AFO $13-9^\circ$). Regarding EC, a similar pattern was seen for both AFOs, where walking with a moderate stiffness reduced EC the most (SH-AFO-k4: -21%, DLS-AFO-k3: -16%). **Discussion:** As hypothesized, the advantage of the SH-AFO, as opposed to the DLS-AFO, is that plantarflexion in loading response did not reduce, which may prevent increased tibia progression at this stage. Furthermore, even with the most compliant spring, the SH-AFO improved gait characteristics. Regarding EC, we saw similar patterns between AFOs, despite large differences in stiffness levels. Results imply that optimal spring stiffness is AFO-type dependent and that other properties, such as ROM, also impact on effectiveness.

FP21

WHY, WHERE, WHEN OF LIMB LENGTHENING

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My experience includes approximately 1,500 cases of limb lengthening; procedures were performed for various indications. In our vast experience with leg length discrepancies we have performed external and internal lengthening procedures and combinations of external and internal procedures. From this large number of various lengthening procedures we concluded certain facts for limb lengthening: why, when, where & how it is to be done by each method. Why the Ilizarov method is preferred and which merits & demerits of each method are to be considered. We have also determined a lengthening index & the maximum limit of lengthening for one particular bone. When to use additional methods for poor bone regeneration will be discussed, and the results will be shown. It is generalised information covering all issues regarding limb lengthening.

FP22

LEG LENGTH DISCREPANCY CORRECTED BY TIBIAL LENGTHENING

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The Ilizarov method is of choice for tibial lengthening because it produces distraction. Distraction stimulates osteogenesis of bone and histiogenesis of soft tissue and thereby avoids the need for bone grafting and soft tissue release procedures. The Ilizarov procedure can be used for epiphyseolysis also. We have performed in total 51 lengthening procedures: 27 for polio residuals, 3 for fibrous dysplasia, 9 for congenital pseudarthrosis of the tibia, 3 for fibular hemimelia, 6 for infection and trauma, and 3 for hypoplastic but stable hips. The average age at operation was 15.29 years, the

average frame keeping period was 6.94 months, the average discrepancy that was covered was 5.38 cm, the average lengthening index was 1.68. We performed 42 linear metaphyseal corticotomies and 9 columnar corticotomies. According to our findings, the upper metaphyseal region is the best and the lower metaphyseal region the poorest for corticotomy. We have evaluated our results with respect to 7 evaluation criteria which were: discrepancy covered, frame keeping period, regeneration quality, ROM, deformity correction, complications and patients and surgeon's satisfaction. Our result according to these criteria were excellent in 30 (60%), good in 15 (30%) and poor in 6 (10%) cases. So we conclude that the Ilizarov method is the best method for limb lengthening, which can correct simultaneously all deformities of any etiology as well as length discrepancies.

FP23

POST-OPERATIVE MANAGEMENT OF LIMB LENGTHENING

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In this paper I am going to give you a complete protocol for post-operative management of limb lengthening. There are 5 stages to be considered in the post-operative management of limb lengthening: 1) the latency period, 2) the distraction period, 3) the stabilization period, 4) the dynamization period, 5) the post protection period. In this presentation I will demonstrate the importance of each phase, and how each stage is to be performed. I will illustrate this with examples of patients and emphasize the importance of physiotherapy during each phase. How to overcome obstacles and problems and how they present will be discussed. So this is a complete overview of post-operative management of leg lengthening surgery.

FP24

TRANSLOCATION OF PERONEUS LONGUS TENDON FOR CALCANEUS DEFORMITY BY DR. PATWA'S TECHNIQUE

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The calf muscles are the strongest of the body, and act as the main plantar flexor of the foot. When the calf muscles are paralysed the calcaneus cannot be actively plantar flexed and the body weight cannot be borne on the metatarsal heads of the foot, and thus, push off phase of walking is lost. Because the dorsiflexors of the foot remain unopposed, laxity of the Achilles tendon and posterior ankle capsule occurs. If the long and short flexors of the toes remain intact, their pull on the posterior end of calcaneus, when walking is attempted, is unopposed, which rotates the whole calcaneus plantarward and produces cavus deformity. Gravity also helps in developing forefoot equinus. The plantar fascia contracts and in the immature foot structural changes in bone and joints ultimately produces a calcaneus – cavus deformity. If along with this the foot inverters are paralysed, the patient develops calcaneo-cavo-valgus foot or if the evertors are paralysed, the patient develops a calcaneo-cavo-varus foot. It is extremely difficult to walk with a calcaneus deformity, but the same holds true for the treatment of talipes calcaneus, which is extremely difficult as no other tendon is as powerful as the Achilles tendon to take over its function. Unfortunately no appliance will replace a paralysed triceps surae to prevent a calcaneus deformity from developing and increasing. According to IRWIN, in progressive deformity tendon transfer is indicated as early as 12 months after the onset of disease, as it is a dynamic deformity. Treatment is difficult because: 1) a suitable transfer is lacking, and 2) surgery to correct the deformity needs to be carried out as early as possible. Tendon transfer surgery in the skeletally immature foot is: 1) to

hault progression of the deformity, and, 2) to restore the power of push off. After skeletal maturity, different bony surgery is necessary for foot stabilisation. We have tackled this problem at any age, by operating via a single incision and rotating the heel flap medially and preparing a slot on the posterior aspect of the calcaneal tuberosity to adopt the tendon of the peroneus longus by a button hole pull, to lock it in the slot. We got excellent results in 32 cases (66.6%), good results in 8 cases (16.7%), and poor results in 8 cases (16.7%), with this peroneal translocation method by Dr Patwa.

FP25

HAMSTRING TO QUADRICEPS TRANSFER FOR QUADRICEPS PARALYSIS

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Paralysis of the quadriceps muscle results in severe disability as the knee is unstable and cannot be fully extended and locked in extension, which results in giving way of the knee joint. Because of this, patients try to stabilize their knee by various means like Hand to Knee Gait, extreme internal or external rotation of the affected limb, to stabilise the knee by support of medial or lateral collateral ligament respectively, or by tilting the pelvis when there is concomitant weakness of the gluteus maximus, the quadriceps and the hamstrings. With strength less than grade 3, the patient may develop compensatory hyperlordosis of the spine. To overcome the weakness of the quadriceps, patients may also try to lock their knee by contracting their gastrocnemius muscles, which leads to tendoachilles tightness resulting in secondary equinus deformity. A slight recurvatum of the knee produces stability of the knee if the triceps surae is active. In case of bilateral quadriceps paralysis patients have to crawl. Tendoachilles tightness should not be corrected before seeing the result of hamstring to quadriceps transfer. We have operated 267 cases with hamstrings to quadriceps transfer. Seventeen of these cases were lost to follow-up, so we studied 250 cases treated by Dr Patwa's technique of Hamstring transfer. We got 162 patients (65%) with excellent results, 38 patients (15%) with good results and 50 patients (20%) with poor results because of excessive recurvatum of the knee (>15 degrees). Also restricted flexion and extension of the knee (>15 degrees) were considered as poor result. Even though they were able to walk without support, we arrived to this result as per our own criteria's.

FP26

THE NORWEGIAN EVERYDAY LIFE, EXPERIENCED BY NON-WESTERN IMMIGRANT WOMEN LIVING WITH POLIO

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The purpose of the study is to obtain knowledge on how non-western immigrant women suffering from late effects of polio, experience their everyday life. The aim is to use this knowledge within the field of rehabilitation. The theoretical approach is founded on two cultural perspectives. One perspective is culture within health sciences, emphasizing illness and health. The other is culture as everyday life, emphasizing home life and working life. The study has a qualitative design, using interviewees as a method. An interactionistic perspective is used in collecting and analyzing the empirical data. Five first-generation immigrant women in Norway between the age of 33–46 years old, all with a non-western background were interviewed. They were all infected with the polio virus previous to immigrating to Norway. Results from the first part of the analysis show that the interview-persons want to appear as "normal" people. Exercising an

going for walks is important to maintain their own health, but is also a part of adapting to the Norwegian society. Many of the persons who were interviewed expressed a strong desire for employment. Volunteer work is desired if paid employment can not be attained. The results from the second part show that practical experiences in everyday life are to a large extent determined by dependency on technical aids. Their experiences do not differ from those of ethnic Norwegian women, living with polio and with the same level of function. What differs seems to be other tasks, related to being a mother of young children or being a teenage mother. The conclusion is that the interviewed subjects strive for living a so called general Norwegian everyday life, according to central values related to being active, employed, exercising and being similar to general population. The desire for employment is strongly present and should be incorporated in a rehabilitation perspective.

FP27

STRATEGIES IN DAILY OCCUPATIONS OF IMMIGRANTS WITH LATE EFFECTS OF POLIO

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Introduction: Globalisation implies an increase in migration. Studies have shown that immigrants in Sweden have poorer health than native-born Swedes. Being an immigrant and having a disability is sometimes described as “double vulnerability”. The proportion of immigrants in the population that has suffered from polio is rising. **Aims:** To explore and describe how immigrants with late effects of polio reason and manage their daily occupations. **Methods:** Interviews with 12 immigrants with late effects of polio from Eastern Africa. Data analysis was carried out according to grounded theory. **Results:** Participants were found to struggle with 4 categories: managing physical capacity; promoting occupation performance; influencing self image; and creating a platform for daily living in the Swedish society. **Conclusions:** The participants’ strategies in daily occupations showed a desire to maintain dignity and normality. The strategies were related to their will to master daily occupations, maintenance of social relationships and settlement in the society.

FP28

PHYSICAL ACTIVITY IN PERSONS WITH LATE EFFECTS OF POLIO – A DESCRIPTIVE STUDY

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Introduction: Physical activity (PA) is beneficial for our health and is recommended to be performed 150 min per week with at least moderate intensity. It has been shown that only 38% of adults with a disability meet the international recommendations and in addition, there is a reduction in the levels of PA with increasing age. In persons 65 years of age and older, 15% of those with a disability met the recommendations compared to 26% of those without a disability. Late effects of polio is a disabling condition, mainly affecting mobility. Persons with late effects of polio are advised to be physically active but have difficulties due to their disability. The aim of this study was to describe PA in 81 persons with late effects of polio, and to assess the relationship between PA, various socio-demographic factors and life satisfaction. **Main outcome measures:**

PA was assessed with the PA and Disability Survey (PADS) and a pedometer. Life satisfaction was assessed with the Life Satisfaction questionnaire (LiSat-11). **Results:** The amount of physical activity varied considerably but on average the participants were physically active almost 3 h per day, mostly in household activities. The mean value of the pedometer counts was 6,212 steps per day (SD 3,208). Sixty-nine percent of the participants rated themselves as satisfied with life as a whole. The sum of PADS was positively and significantly related to the number of steps ($r=0.39$, $p<0.001$), age ($r=0.26$, $p<0.05$) and to the level of global satisfaction with life ($\rho=0.23$, $p<0.05$). The number of steps was also positively and significantly associated with the level of global satisfaction with life ($\rho=0.37$, $p<0.001$). **Conclusions:** Despite a progressive physical disability, people with late effects of polio are physically active, but much of the activities are performed as part of their household activities and not as traditional exercise. The relationship between PA, age and life satisfaction further supports the general contention that an active lifestyle is an important factor for perceived well-being among people aging with a disability.

FP29

NEW 20-YEAR FOLLOW-UP NATIONAL SURVEY ON POLIO SURVIVORS IN NORWAY

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Aim: We present results from a new nation-wide survey on polio survivors in Norway 2014, 20 years after the former national survey in 1994. The aim of the survey was to explore the situation and needs of the aging polio population with regards to their physical and psychosocial situation, as well as their needs for health care. **Background:** Several international surveys on polio survivors have been performed since the onset of late effects of polio. Two nation-wide surveys have been conducted in Norway; one in 1988 by the Norwegian Disability Union (Alm Andreassen), the other by the National Society of Polio Survivors, LFPS, in collaboration with professionals (Øyhaugen & Lobben 1994). The questions in the latter survey were based upon those asked in national surveys from USA (Halstead 1985, 1987), France (Diard et al. 1994) and Denmark (Lønnberg 1993), but more questions covering the acute- and rehabilitation phase of polio survivors were included in the Norwegian study. The Norwegian survey confirmed the various health problems in the polio population, and the survey had great impact on initiating further research and generating comprehensive treatment programs in Norway. The present study is a 20-year follow-up of the “Polio Survey, LFPS, 1994”, and to our knowledge, the first national follow-up survey in two decades. The study is led by LFPS in collaboration with Sunnaas Rehabilitation Hospital. **Method:** A postal questionnaire was distributed January 2014 mainly to registered members of LFPS, including more than 2000 persons, including most of those participating in 1994 ($n=1,444$). The questionnaire covers issues like the acute poliomyelitis, rehabilitation, peak recovery, psychological, social and medical conditions. In addition standardized questionnaires are used to make comparisons to the general population regarding mental health, quality of life and concomitant diseases. We plan to present an overview of the main findings, especially focusing on unmet health care needs in the polio population 2014, that should be addressed by the Norwegian health authorities.

WORKSHOP LECTURES (WS1–WS19)

WS1

MANAGEMENT OF BLADDER AND BOWEL SYMPTOMS**Lise Kay, MD, Anne Marie Eriksen, PT***PTU Danish Association of Polio and Accident Victims, Rodovre, Denmark*

Bladder and bowel habits are influenced by various factors: neuromuscular function, oral intake, culture, psychology, upbringing, and toilet access. Polio survivors may be challenged in several of these fields and consequently have a special risk of having bladder and bowel symptoms. Polio survivors who experience bladder and bowel symptoms should primarily have a screening to exclude that other diseases are causing the symptoms. In case of bladder symptoms this would usually imply a urinary test for blood, an ultrasound, and a blood test of PSA (men). For bowel symptoms it usually implies a colonoscopy of the bowel. When other disease has been excluded, focus can be put on the factors first mentioned. Initially a patient history should be taken including drinking and toilet habits, diet, and physical challenges at toilet visits. For bladder symptoms a voiding and drinking diary should be fulfilled, together with a standardized questionnaire on bladder symptoms. A physiotherapeutic assessment of the pelvic floor is to be carried out. It includes inspection of the pelvic floor and vaginal palpation of muscle tonus both at rest and during contraction. This work-up usually reveals several points for improvement. In many cases incontinence can be eliminated or minimized when structure and changes in toilet-habits, fluid-habits, and training in voluntary use of the pelvic-floor are implied. Bowel symptoms are generally addressed parallel to bladder symptoms, but may often require support by a laxative. A laxative prevents overextension and thereby facilitates bowel contractions. Laxatives can seldomly be misused. Constipation, overextension and the weak contractions are much more risky to bowel function than overuse of laxatives. Laxatives that function by increasing nerve activity in the bowel are the only exception to this rule. In severe cases of constipation irrigation of the bowel as self management scheme can be necessary and very seldom different operations may be the last solution. If symptoms are not relived by the above, one should consult specialists in urology or gastroenterology, who are experienced in bladder and bowel problems. *Summary and Key points:* Toilet habits are influenced by various factors: neuromuscular function, oral intake, culture, psychology, upbringing, and toilet assess all which may challenge polio-survivors. If screening does not reveal other disease, improvement can usually be obtained by addressing these factors.

WS2

EXOSKELETONS FOR ENHANCEMENT OF PATIENTS WITH NEUROMUSCULAR DEFICIENCIES**Frans CT van der Helm, PhD¹, Heike Vallery, PhD¹, Gerard Dunning, MSc¹, Just Herder, PhD²***¹Biomechanics and Biorobotics group, ²Precision and Microsystems Engineering, Delft, the Netherlands*

Patients with neuromuscular deficiencies miss sufficient muscle force and often also muscle coordination. Active and passive exoskeletons can supply additional forces e.g. to compensate for gravity and to generate cyclic motions. Passive exoskeletons use springs to compensate for gravity. Active exoskeletons have actuators for an additional supply of energy if the patients lack sufficient muscular capacity. In addition, the active exoskeletons can also stabilize motions. Examples will be shown for a passive exoskeleton for the upper extremity, with spring compensation for gravity. The patient can use the little muscular control left for generation of the desired motion. The exoskeleton is light weight and meant to be worn underneath the clothing. Another examples are a passive and active exoskeleton to assist walking. The passive exoskeleton is meant for patients with lack of muscle force,

e.g. elderly and patients with muscular dystrophy. The exoskeleton stores and releases energy using springs during the walking motion, in order to preserve energy. The active exoskeleton is meant for patients with spinal cord injuries, with no active control of their legs. It uses six actuators for the hip and knee, and has supplementary control for stabilization of the walking motion. The ultimate aim is to enable patients to walk without crutches.

WS3

THE CAREGIVER AND ISSUES IN SOCIETY**Jan Lexell, MD, PhD¹, Mary McFarlane, BSc (Hons)², Anja Horemans, PhD³***¹Department of Health Sciences, Rehabilitation Medicine Research Group, Lund University, Lund, Sweden, ²Ireland, ³Dutch Association for Neuromuscular Disorders (Spierziekten Nederland), Baarn, The Netherlands*

Post-polio syndrome (PPS) is a condition without boundaries and these boundaries expand as the polio survivor ages. Given that the condition starts to become noticeable some 20 to 40 years after the initial polio infection, many will have formed partnerships, families and enjoyed a productive life. However, as PPS develops the survivor may become increasingly, if unwillingly, more dependent upon their partner and/or family. Until recently the role of the caregiver in the management and progress of PPS has been unrecognised by society in general as well as statutory and supportive bodies, such as health and social services. This workshop will explore the role of the caregiver in the life of the polio survivor and demonstrate the pivotal role they play, and how they need support. It will also explore and allow those participating to share their own experiences and how different and differing social support schemes, monetary, and attitudinal issues affect their lives and those for whom they care. Examples will be drawn from countries within older established social support schemes from within the EU as well as newer emergent nations. Others will be drawn from countries where polio is still a recent memory or an ongoing problem.

WS4

THE POLIO-CLINIC**Katharina Stibrant Sunnerhagen, MD, PhD***Sahlgrenska University Hospital, Gothenburg, Sweden*

The polio clinic started in 1994 and is organized as a multidisciplinary team including a physician, nurse, occupational therapist, physical therapist, social worker and a secretary. When first seen, the individual goes through basic laboratory examinations and is then assessed by the nurse, the physician, the physical therapist, and the occupational therapist. A team conference takes place, treatment plan are discussed and referrals for specific polio examinations were made. Need/acceptance for assistive devices and home modifications are identified and referrals made. If needed, appointments with the social worker occur. *Questionnaire.* The subjects were mailed a questionnaire before the first appointment. It contained questions about patient demographics, age at acute polio onset, body part(s) affected, onset of new or increasing health problems related to the polio disease, other diseases and the current use of walking devices. If necessary, the questionnaire was completed during the visit to the physician. *Peak expiratory flow.* The tests are performed with a portable peak flow apparatus. If the function is reduced to 50%, referrals are sent to the pulmonologist for further investigation. *Walking.* Spontaneously (SW) and maximal chosen (MW) walking speeds were measured as the time taken to walk 30 m indoors. The test started with the spontaneously chosen speed. The subjects used their own footwear and walking devices if necessary. *EMG.* The EMG examination together with the muscle strength measurements was conducted at the laboratory, after the visit to the clinic. The

presence of polio-affected muscles s first determined according to the clinical history of the subject. *Muscle testing* was performed using a BioDex. Peak isometric strength was measured at a 60° knee angle during extension and flexion. Maximum isokinetic strength was measured at 60°/s during extension and flexion. Isometric endurance was measured as the time the subject was able to keep 40% of his isometric peak torque at a 60° knee angle. All results were normalized for age and gender. So far, more than 900 patients have been. All data are entered into a database for research purposes. There are more females (52%) and the average age when seen at the clinic is around 59 years of age. Approximately 20% are born outside Europe and of the rest, only around 4% outside Scandinavia. Age at polio-infection is on average 7 years (range 0–39 years of age).

WS5

AN INTERDISCIPLINARY MODULAR PROGRAMME FOR POST-POLIO PATIENTS

Axel Ruetz, Dr Med

Katholisches Klinikum Koblenz, Deutschland

Round about 70.000 German survivors of polio are attended to in an acute hospital with an attached ambulance in Koblenz. It is typical of the German health system that diagnosis and acute intervention with stationary indications are adducted in hospitals; rehabilitations of pre-treated and pre-diagnosed consequent conditions of poliomyelitis are adducted in rehabilitation clinics. This institution for secondary diseases after paralytic polio process has been admitted by the Ministry of Health for the first time and is unique in Germany. The concept of acute treatment is carried out modularly and interdisciplinary, depending on the patients' needs. Module A is supposed to diagnose and treat loss of function, leftover capacities and the prognosis of post-polio syndrom (PPS). Pneumologically, examinations of lung function, respiratory strength and sleep take place, where required with ventilation supply. In order to make a diagnosis and to acknowledge the stadium, imaging methods, especially lavish MRI examinations, CT and functional X-rays, are being used. Neurological examinations with electrophysiological results are being applied for diagnosis of exclusion and of process. Module 1 serves for orthopaedic treatments of specific and painful decompensations with PPS. Orthopaedically, the classification of function and stadium is being accomplished through measurement of efficiency in following, function improving activities such as interventional pain therapy – juxtaspinal or at the joints –, orthotic supply. Physiotherapeutic Module 2 is supposed to achieve function improvements of the specific handicaps after polio and with PPS. Module 3 will help in case of failure of conservative orthopaedic therapies with adverse effect of functions and painful diseases under consideration of special anaesthesiologic allowance and operative risks by operations at soft parts, bones and joints. The function of Module 4 is to recondition polio consequent conditions – in connection with Module A and Module 1–3 and in form of a stationary subsequent measure in a clinic which is certified by the Bundesverband Polio e.V. The special ambulance of the Polio Centre at the Catholic Clinic is a first-contact and consequent supply institution with free access like public health, which conducts around 1000 consultations per year as well as 150 first investigations and ambulant examinations. *Conclusions:* For the first time, we present the concept of an interdisciplinary modular programme for PPS patients in Koblenz, Germany.

WS6

INTERDISCIPLINARY APPROACH OF POLIO AND POST-POLIO SYNDROME IN A REHABILITATION CENTER IN CATALONIA (SPAIN)

Enric Portell, MD

Institut Guttmann, Badalona

Institut Guttmann, located in Barcelona, is a private center that also provides care of patients from the National Health Service. This is a leading hospital for medical treatment, surgery and comprehensive rehabilitation of patients with spinal cord injury, acquired brain damage or any other serious neurological disability. It was founded in 1965, and was the first hospital in Spain for the treatment of spinal cord injury and brain damage. With the years it has extended its facilities, and we started to take care also of patients with polio or post-polio syndrome. In 2007 the unit of polio and post-polio was created, and since then we have followed more than 600 people. There is a multidisciplinary team, including physician, nurse, psychologist, occupational therapist, physiotherapist and social worker with the support of neurology, psychiatry, orthopedic surgeon, orthopedic technician and neurophysiologist. In Spain there are no other centers or specific units dedicated to the care of polio/post-polio patients. We serve patients from all Spain, but mainly from Catalonia. We basically offer an initial assessment of functional, neurological and respiratory status. If it is necessary we realize complementary studies like EMG, sleep study, spirometry and radiology. The main objective are to establish the proper diagnosis of post-polio syndrome if this is the case, and to design the appropriate treatment and follow-up. We offer the following evaluation/treatment:

- Physiotherapist and occupational therapist: Advise on physical exercises and assessment of orthosis and technical aids. Training in the handling of wheelchairs and adaptations or reforms at home.
- Orthopaedic technician: Assessment for braces if needed for walking.
- Psychologist: If there is a maladaptation to the change in functional status, there are individual or group therapy specifically designed for them. If memory problems arise, a neuropsychology team is available.
- Social worker: Revise issues related to their work, including retirement options. Provide the appropriate contact with the different affected associations (APPCAT in Catalonia).

WS7

GAIT STUDIES IN POLIOMYELITIS

Isabelle Laffont, MD, PhD¹, Hilde Ploeger, PT, MSc², Christina Brogårdh, PT, PhD³

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After years of stable functioning, many polio survivors experience new or increased muscle weakness along with abnormal muscle fatigue, generalized fatigue, and joint pain and/or muscle pain (so called post-poliomyelitis syndrome). These impairments often lead to reduced balance, risk of falling, reduced walking speed and walking distance, and have a huge impact on daily functioning and quality of life. Maintaining or improving walking ability is therefore a common goal in rehabilitation. In order to reach such goals, gait and functional restrictions related to gait need comprehensive assessment. In this workshop we first present and illustrate how gait can be observed clinically. Common patterns of post-polio patients' gait and their functional consequences are described. Based on videos, we try to explain the way muscle weakness can affect gait smoothness or efficiency. Thereafter, we present in more detail how gait can be assessed by using different assessment tools, with the 'International Classification of Functioning, Disability and Health' (ICF) as framework. We describe how gait biomechanics and effort (ICF component 'body functions and structures') can be assessed with instrumented gait and gas-exchange analysis respectively, and how gait performance (ICF component 'activity and participation') can be assessed with self-reports and quantitative measures. Here, self-reported walking limitations are described by the Walking Impact Scale -12 (Walk-12), and quantitative assessments with the 10 meter Comfortable and Fast Gait Speed test, the 6-minute walk test and the Timed-Up & Go test. Furthermore, we present on the effect of orthoses interventions, since orthosis are one of the most frequently used interventions to improve gait and gait related problems in polio survivors. This example allows us to

illustrate how instrumental gait analysis can complement clinical and functional assessment. The outcome measures discussed in this workshop can be used in clinical practice to develop and evaluate individual rehabilitation goals and interventions on gait, but also for research purposes.

WS8

CLINIMETRICS – WHAT SHOULD WE MEASURE FOR WHAT PURPOSE?

Anita Beelen, PhD¹, Christina Brogårdh, PhD², Józef Opara, MD, PhD³

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Common impairments in persons with post-polio syndrome, such as muscle weakness, muscle fatigue, and pain often lead to activity limitations and participation restrictions which can impact on quality of life. The widespread functional restrictions that many polio survivors perceive require a comprehensive assessment and description of their disability. The ICF developed by the WHO, provides a unified language and framework for the description of functioning and disability in polio survivors. Health domains are classified in the “body functions and body structures” component and in the “activities and participation component”. As the functioning and disability of an individual occurs in a context, ICF also includes contextual factors containing environmental factors and personal factors. Another important concept that should be assessed, additional to the concept of functioning, is quality of life. While functioning refers to limitations and restrictions related to a health problem, quality of life refers to how someone feels about these limitations and restrictions. Assessment of functioning, disability and quality of life is important for diagnostic purposes. Repeated assessments can assist in monitoring disease progression, provide prognostic information and be used for evaluating the efficacy of interventions both clinically for each individual and in the context of clinical trials. The aim of this workshop is to describe functional assessments in polio survivors, using the ICF framework. We will present and discuss different outcome measures within the ICF domains (body functions, activity and participation) together with clinimetric properties that are relevant to all outcome measures (such as validity, reproducibility, responsiveness, and interpretability). Clinicians and researchers should choose sound outcome measures based on the construct of interest, together with the available evidence on the clinimetric properties. To allow comparison between studies in polio survivors, a standard set of outcome measures (ICF core set) covering the most relevant ICF concepts and quality of life should be agreed upon and is recommended to be used in every study. *Key points:* 1) A comprehensive assessment of functioning, disability and quality of life should form the basis for the individually tailored rehabilitation program in polio survivors. 2) The choice of outcome measures for functional assessment should be based on evidence of clinimetric properties for polio survivors. 3) A standard set of outcome measures should be internationally agreed upon and used in studies in polio survivors.

WS9

EXERCISE – FROM THEORY TO PRACTICE

Eric Voorn, MSc¹, Deirdre Murray, BSc, PT, PhD², Merete Bertelsen, PT³

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Aim: To equip therapists with the skills and knowledge to use exercise to improve polio survivors' general condition and function

and to reduce risk of life style related diseases. This workshop will summarize the research on exercise for polio survivors. The main focus will be on practical examples and of how to plan an individualized exercise program for a polio survivor. *Cardiorespiratory exercising:* Most guidelines recommend training intensities based on the maximal aerobic capacity. In polio survivors, maximal testing is however contraindicated and, moreover, not feasible in all individuals. Submaximal exercise testing is therefore strongly recommended. A submaximal protocol, as applied in Amsterdam, will be presented and how this can be used to determine training intensity for individual patients in clinical practice. *Strength exercising:* Muscle strength in polio survivors can be assessed using manual muscle testing, hand held dynamometry or fixed dynamometry. There has been a reluctance to prescribe strengthening exercise, due to the fear of provoking further weakness. However, there is some evidence that strengthening exercise can safely be used to maintain muscle strength in muscles with mild to moderate weakness. Exercise prescription based on the use of low to moderate resistance, frequent rests and slow progression with ongoing monitoring of signs of muscle overwork is recommended. Warm water exercising and group training Exercising in warm water has always been a popular way of training polio survivors. The water makes movements possible, that are not possible on land, and the warm water makes tight muscles relax and gives a feeling of pain reduction. Different aspect of training (cardiorespiratory exercises, balance training, general training and relaxation) can be done in a pool. Based on clinical practice in Denmark, examples of exercises in water and training in groups will be presented. *Summary:* Polio survivors present to rehabilitation services with problems which include deconditioning, muscle weakness, fatigue, pain and declining mobility. Exercise, including aerobic training, strengthening and flexibility utilizing a variety of exercise formats can effectively improve polio-related disability.

WS10

ORTHOTICS – GUIDELINE-BASED PRESCRIPTION PRACTICE

Merel-Anne Brehm, PhD¹, Parwin Yari, MD¹, Tom Gort, CPO²

¹Department of Rehabilitation, Academic Medical Center, University of Amsterdam, Amsterdam, ²OIM Noppe Orthopedie, Noordwijkerhout, The Netherlands

In rehabilitation practice, the prescription of lower limb orthoses is based more on craftsmanship than on evidence. Few studies in neuromuscular disorders, including polio and PPS exist on the effectiveness of these devices. In 2011, the AMC, in collaboration with a platform of experts, published a national guideline on the prescription of leg orthoses, following the Process description of Medical devices. The need for using such guidelines in clinical practice increases, as new and costly technologies become available. Moreover, in many countries reimbursement will become increasingly dependent on proven (cost-)effectiveness of these new devices. In this workshop we will share clinical experiences and scientific evidences to show how the guideline may support clinicians and other healthcare professionals in applying treatment more effectively. First, we will demonstrate what steps are involved in identifying the care need of the patient, which includes conducting an intake and performing a physical examination. Furthermore, we will show how 3D gait analysis, in addition to physical examination and clinical observation can be useful in analysing the gait abnormalities underlying the complaint of the patient, and deciding on the required action of the orthosis. Second, the current state-of-the-art in lower limb orthotics is highlighted, including stance-control orthoses and prepreg carbon composite shell materials. Also aspects regarding gait training with these novel devices are discussed. Thirdly, the importance of judging the clinical relevancy of the orthosis is addressed, which involves an evaluation of the effectiveness of the orthosis, using outcome measures that capture changes in relevant aspects of walking and standing.

WS11

SPEECH & SWALLOWING THERAPY

**Sandra Offringa, Speech Language Therapist¹,
Paivi Annikki Tupula, Speech Language Therapist²,
Thomas Lehmann, MD³**

¹Department of Rehabilitation, Academic Medical Center Amsterdam, Amsterdam, The Netherlands, ²Sunnaas Rehabilitation Hospital, Norway, ³Schweizerische Interessengemeinschaft für poliopspätfolgen (SPIS), Suisse

Goal: Clinical practise: discussion which problems may be present and its treatment. Although bulbar involvement affecting speech and swallowing is a “minority” among polio patients, some specific late problems are seen in post-polio care. These impairments in functioning can have a disabling effect on the patient’s daily life. Eating and drinking can take a huge amount of time and energy, leaving for the rest of the day little time to do other activities. Aspiration as a result of swallowing difficulty must be prevented as good as possible. Verbal communication forms an essential part of many people’s lives. (Chronic) respiratory insufficiency as well as dysarthria (speech and articulatory problems) can have great impact on Quality of Life. These consequences can be due to post-polio syndrome as a lasting consequence of acute polio as well. Best treatment options suggest speech therapy as part of a multidisciplinary approach. In this workshop, the speech- and swallowing difficulties are outlined within the relevant domains of the International Classification of Functioning, Disability and Health. The suggested treatment is discussed along a model of clinical decision-making, HOAC II.

References:

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2. World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva, Switzerland; 2001.

WS12

COPING & PSYCHOLOGICAL ISSUES – OLD HABITS DIE HARD

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Living with polio is a life long coping experience. In this workshop two cases will be presented. Different coping strategies employed by people with post-polio syndrome (PPS) (a European patient with PPS and a patient with PPS originating from outside Europe) throughout their lives will be discussed. In clinical practice we observe that some coping strategies managed by most European patients with PPS loose their functionality over time and become dysfunctional, obstructive and sometimes even harmful. In non-European patients we see the same pattern as in the European population. However, these dysfunctional coping strategies interact quite often with severe psychosocial problems and above all there are sometimes difficulties to express needs and emotions in the new language. The aims of this workshop are 1) to enhance recognition and deepen understanding of functional versus dysfunctional coping strategies, and 2) to learn about opportunities to develop new, more adaptive coping strategies with subsequent improvement of physical and emotional well-being in both groups.

WS13

INTERNATIONAL EXCHANGE OF EXPERIENCES BETWEEN POLIO SUPPORT GROUPS

John R McFarlane, Fellow Birmingham University, PhD¹, Els Symons, MSc²

¹President of European Polio Union, Tullamore, Ireland, ²Board member European Polio Union and Chair Polio Supportgroup of

The Dutch Patients Association of Neuromuscular Disorders (SN), The Netherlands

Introduction: Groups specifically designed and operated to assist polio survivors have been in existence for many years, even decades as is evidenced by the 75th anniversary of APB Belge last year and the British Polio Fellowship this year. However, and regrettably until quite recent times there has been little or no inter or even intra country transfer of experience and knowledge. With the formation of the European Polio Union in recent times we can see cross flow of knowledge and experiences occurring in the wider, but still mainly European based “polio family”. The challenge is to transfer this knowledge and experience into third world and developing countries and countries and regions within the European sphere where no or little polio support infrastructure exists. It is worth remembering that the last person in the world to contract polio will, if a child, need support of one kind or another for probably 60+ years. **The Way Forward:** Everybody whether a polio survivor, family member, carer or medical professional have a wealth of knowledge, experiences and tips about how to “survive” and contribute to the worldwide “polio family”. These need to be gathered and transmitted to others in a friendly, informative, educational and non patronising manner. The questions that need addressing, and perhaps expand upon are: – How do we bring together the body of knowledge and should that be performed by polio survivors and/or their groups only and/or others and – Where in this process do professionals fit in? Who should bring the gathered knowledge together and authenticate it for veracity? In what manner and through what routes can this all be distributed and how can feedback be incorporated? Please remember that this gathering of knowledge is a two way affair. There is, for example, much from the Indian sub continent that can teach us in the West. Medical professionals from that part of the world will have seen polio in the raw.

WS14

NUTRITION FOR POST-POLIO SYNDROME

Frances Quinn, MSc¹, Coby Wijnen, RD²

¹The Walton Centre for Neurology and Neurosurgery, Liverpool, UK, ²Spierziekten Nederland (dutch patient association for neuromuscular diseases), Baarn, The Netherlands

This workshop focuses on nutrition relevant to mobility and health in polio survivors. Ideally, all required nutrients are provided while maintaining a healthy weight to reduce stress on limbs and lower the risk of heart and vascular disease. Highly important is preservation of muscle mass. A recent study of experiences of UK polio survivors with weight management provided evidence of the difficulties involved. Many were unable to maintain a healthy weight, while others only succeeded by strictly controlled regimes. Some reported that a difference of only a few kilos had a significant impact on quality of life. Approaches used were similar to the general population; the most common being a self-chosen diet and second most common combining self-chosen diet and exercise. However, the inability to exercise was seen as a major barrier. Some respondents indicated calorie intakes low enough to risk nutritional deficiency and others that the impact on energy and health prevented them from maintaining a low enough intake to match their limited physical activity. Most polio survivors have only a small imbalance in energy need and expenditure, which can still result in overweight after many years. Careful dietetic management can lead to weight loss without losing muscle mass. Loss of muscle mass in combination with aging and reduced mobility calls for an adequate protein intake which may preserve muscle strength. Low vitamin D levels, associated with low muscle strength, require supplementation. The general advice is to strive for a healthy body weight, with adequate protein intake and energy, fibres, calcium from dairy products, vitamin D and other micronutrients, in combination with exercise. Secondary consequences of reduced mobility can be constipation and osteoporosis. Sometimes dysphagia and/or fatigue can lead to undesired weight loss. **Key points:** In the short time available, the aims are

to provide an update on current knowledge and good practice, to agree research priorities and to encourage discussion of key points raised. Lastly, we propose a call to action to produce nutrition guidelines specific for this population.

WS15

MULTIDISCIPLINARY ONE-DAY REHABILITATION TEAM EVALUATION FOR POST-POLIO SYNDROME PATIENTS

Parwin Yari, MD, Anne Carien Beishuizen, PT, Dorien Toor, OT, Liesbeth Eggink, SW

Department of Rehabilitation, Academic Medical Center, Amsterdam, The Netherlands

The AMC serves as the Post-Polio Expert Center for the Netherlands and each year on average 90 new patients are seen for diagnosis and therapy or for advice. Referrals originate from all over the country. Many patients suffer from post-polio syndrome. Since 2007, the AMC offers a multidisciplinary one-day rehabilitation team evaluation for patients with polio-related complaints. The focus of this day is not on medical diagnosis but on supporting patients in managing their functional problems and physical complaints. The procedure is as follows: After initial screening the rehabilitation specialist together with the patient, decides on participation in this multidisciplinary evaluation. The criterion is that patients must have multiple problems, and questions on how they can better manage their symptoms and increasing disability. Two weeks before, patients fill in a questionnaire and formulate their questions for the team. These questions guide the multidisciplinary assessment on the day itself, during which a rehabilitation specialist, physical therapist, occupational therapist and social worker see them. Afterwards the team meets to reach a common conclusion on the findings and advice for further therapy. The day ends with a joined meeting of the team with the patient to summarize and discuss findings and advices. The patient is sent a full written report afterwards. Six weeks later follow-up of advices is checked by phone. The most frequently addressed issues concern the reduction of pain, tiredness and overload, improving fitness, exercise and sport, advice on home and work adjustments, and on the use of walking aids. Social and emotional items most discussed are how to deal with physical complaints, with acceptance, with fear of being dependent and with concerns about the future. Depending on the distance, patients are further treated in the AMC or referred to rehabilitation centers with expertise in neuromuscular diseases in the vicinity of their homes.

WS16

INTERNATIONAL RESEARCH COLLABORATION

Kristian Borg, MD, PhD

Department of Clinical Sciences, Division of Rehabilitation Medicine, Karolinska Institutet, Stockholm, Sweden

Patients, young scientists and experienced scientists will discuss future directions for post-polio research at a round table. The area is following the ICF spectrum from genetic and molecular aspects through function and activity to quality-of-life. Collaboration within European and International networks will be defined and highlighted.

WS17

PHYSIO- AND OCCUPATIONAL THERAPY – INSPIRATION ACROSS BORDERS

Merete Bertelsen, PT¹, Katja Appelin, OT, MSc²

¹The Danish Society of Polio- and Accident Victims, Copenhagen, Denmark, ²Department of Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden

Aim: The aim of this workshop for professionals is to inspire therapists in ways of assessing and managing polio survivors and to exchange experiences and clinical practice within the audience. **Content of workshop:** Physio- and occupational therapy has always played a major role in the rehabilitation of polio survivors. The majority of typical complaints of a polio survivor (fatigue, decreasing level of functioning and pain) can be dealt with by therapists. To be able to treat and advise a polio survivor adequately, the therapist must record a thorough patient history including acute polio situation, limitations and resources in body functions and structure, activity/mobility and participation in society. Examples of tests used to measure these aspects before and after intervention will be presented. Physio- and occupational therapy will typically comprise pain reduction, recommendation on technical aids and bandages, physical exercise, ADL training, patient education/empowerment and energy management. Rehabilitation of a polio survivor will in many cases need a multidisciplinary team comprising all or some of the mentioned professionals: Medical doctor, occupational- and physical therapist, psychologist, orthopedic technician, social worker and dietician. In this workshop we will focus on the role of occupational- and physical therapy in the rehabilitation process of the polio survivor based on clinical practice in Sweden and Denmark. We encourage the audience to participate in sharing their experiences in working with polio survivors in different countries. **Summary:** A Scandinavian approach to rehabilitation, examples of assessment, testing and management of typical problems of polio survivors will be presented.

WS18

DEFORMITY CORRECTION IN POST-POLIO RESIDUAL PARALYSIS

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Department of Orthopaedic Surgery, St Stephen's Hospital, Tis Hazari, Delhi, India, Department of Orthopaedic Surgery, Academic Medical Center, Amsterdam, The Netherlands

In this workshop orthopedic treatment options will be discussed based on clinical case presentations of musculoskeletal deformities in polio patients of various ages. Emphasis will be given to specific issues that have to be considered when treating patients with orthopedic problems related to polio such as functional outcome, prevention of worsening, and long term perspectives.

WS19

WHEELCHAIRS FOR POLIO SURVIVORS

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Goal: Polio survivors frequently use wheelchairs in their daily lives. Some patients use their wheelchair occasionally, for long distances. Other patients are completely wheelchair-dependent and use their wheelchair very intensively. For the wheelchair-user, it is, especially in the beginning, very difficult to determine which wheelchair is the right choice. There are a lot of brands and types on the market. Which wheelchair is best for you, depends on your personal situation. It depends on where you are going to use the wheelchair, when, how often, for how long and if you need a manual or an electric wheelchair. It is also important to know if there are any requirements for portability. Besides the right wheelchair, an optimal sitting position in the wheelchair is also very important. With the right individual adjustments, pain, such as back pain, and fatigue can be prevented and optimal movement can be created. In this workshop the focus will be on the biomechanics of sitting. The question 'is there an ideal seated position?' will be answered and the translation will be made to sitting in a wheelchair. The different options regarding wheelchairs will be discussed with their advantages and disadvantages.

POSTER PRESENTATIONS (PP100–PP130)

PP100

DIVING MODIFICATIONS FOR POST-POLIO SURVIVORS – THREE CASE STUDIES

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Introduction: The main recommendations for promoting the quality of life (QOL) of post-polio (PP) survivors include psychological and social support, and promoting health through cessation of smoking, weight maintenance, and physical activity. Scuba diving is one of the most accessible sports for disabled people. Participation in a diving club has the potential to contribute both to the physical and to the mental components of QOL. The aims of this case series are to describe the profile of 3 PP survivors who participate in diving on a regular basis and the necessary modifications to make this sport suitable for them. **Methods:** This is a case series study. Data was collected by a self-administered questionnaire. **Results:** The study comprises 3 60 year-old post-polio, paraplegic, males who are completely independent in Activities of Daily Living (ADL). The SF-12 physical and mental scores of these cases range between 24.5–39.3 and 50.2–63.0, respectively. All 3 expressed feelings such as freedom and relaxation in an under-water world. They also enjoyed the social interaction accompanied with the diving activity. Adapting scuba diving for the participants related to equipment, dressing, getting in and out of the water, and diving technique. **Conclusions:** The 3 participants enjoyed the benefits of diving despite their disability. The required modifications were relatively easy to achieve. These results should encourage other PP survivors to take part in challenging sports suitable for them. Future studies should evaluate the effects of diving on both physical and emotional abilities of a larger group of PP survivors.

PP1001

POLIO AUSTRALIA'S ANNUAL HEALTH AND WELLNESS RETREATS REVIEW: THE IMPLICATIONS FOR PARTICIPANTS ON HEALTH LITERACY AND HEALTH OUTCOMES

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In an evaluation and review of the 4 "Health and Wellness Retreats" run by Polio Australia to date in New South Wales (2010), Victoria (2011), Queensland (2012), and South Australia (2013), all participants were sent a 10-question survey inviting them to self-report on whether the experience has resulted in any improvements in their Health Literacy and Health Outcomes. Like most developed countries, Australia's population is ageing, resulting in a rise in chronic diseases – which includes the late effects of polio and/or post-polio syndrome. Managing this unprecedented demand on health services depends on people's ability to access and utilise information appropriately, therefore the need to improve health literacy is paramount. Polio Australia's annual Health and Wellness Retreat model was adapted from Polio Health International's Post-Polio Wellness Retreat held in Warm Springs, USA in 2009. The aim of the Retreats is to provide a holistic approach to managing the late effects of polio and finding life balance, with each day focussing on a different aspect of health and wellness: Body, Mind and Spirit. The Retreats have become a flagship program for Polio Australia, supporting its vision of ensuring that all polio survivors have access to adequate support and information together with comprehensive, consistent health care from a range of well-informed and educated professionals. The 10 Health Literacy and Health Outcomes survey questions were based on Professor Don Nutbeam's conceptual model of 'health

literacy as an asset'. In addition to questions about changed health behaviours and practices, the survey also sought to identify any improvement in people's capacity to advocate for both themselves and others in relation to getting support to manage the late effects of polio, and their participation in changing social norms and practices such as raising awareness about physical access issues within their communities. The results of this survey provide essential statistical data for use in reports, funding submissions, lobbying government, health related publications, and further research.

PP102

HYPNOTHERAPY; COULD IT BE PART OF A MULTI DISCIPLINARY APPROACH IN THE MANAGEMENT OF POST-POLIO SYNDROME?

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This paper proposes using hypnotherapy as one approach in the acceptance and management of post-polio syndrome (PPS). Central to any intervention is the potential impact on individual quality of life. Hypnotherapy may be successfully used in resolving psychological traumas suffered by polio survivors and as a personal tool for PPS symptoms. It is widely documented and generally accepted, that PPS is a condition without a cure. What seems to have evolved are medical and surgical interventions to treat conditions, their presenting symptoms, orthotic supports to aid mobility and various self directed coping techniques. Trauma has been defined as 'any bodily injury or wound' or 'an experience that produces psychological injury or pain'. It is a common denominator in polio survivors. Conversations with fellow survivors confirmed how difficult it was to cope with the unacknowledged and often repressed, previous traumatic events. We could all relate to several of the well documented experiences of abandonment, rejection, isolation, confusion, pain and abuse (physical and emotional). Other research identifies concepts that characterise typical attitudes and behaviours adopted by polio survivors before the onset of PPS. It was clear that these traumatic events, experienced during childhood and adolescence, coloured an ability to respond positively to behavioural adjustments subsequently required, on diagnosis of PPS. Research and anecdotal information validate the traumatic legacy, and subsequent learnt behaviours of polio survivors, by documenting chronic stress, anxiety, depression and Compulsive Type A behaviour. These are also symptomatic in the wider general population and are prevalent in the case studies of my clients. There is strong evidence for the efficacy of hypnotherapy for identified stress and trauma related symptoms but no linked evidence to the treatment of PPS. My contention and contribution is that hypnotherapy could be a cost effective, efficient, non-invasive intervention to minimise, or control, the various conditions associated with PPS. Self hypnosis is also easily taught. This consideration is underpinned by personal research and experience of both polio and PPS, anecdotal evidence from others sufferers and my experience as a hypnotherapist.

PP103

A LIFE REVIEW FOR THOSE WHO EXPERIENCED POLIO

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A life review is generally known to be a method of looking back at one's past to give a clearer understanding of what one lived through in order to see more fully one's experience. There are several ways to accomplish this goal. One could do a personal story telling to family and/or friends. One could do an oral history or write an autobiography. One could video tape one's history. There may be more. The purpose of this life review is to examine one's experience with

having had polio. What happened? What is happening? How has one dealt with the effects and even late effects of this disease. The following questions are meant to help enlarge one's understanding of one's life journey with polio. Some goals could be:

- Promote increased awareness, and knowledge of one's past.
- To provide a venue for discussion with family and/or friends.
- To provide increased meaning of one's past.
- To possibly educate others about the effects of one's journey with polio.

Since so many of post-polio survivors are advancing in age and since many of us will be gone within the next 30 plus years, it could be incumbent to leave a record, to bring an opportunity to look back, to consider life's ups and downs, and construct a sense of integration prior to one's demise. This could be a hopeful project and one in which our families and friends could benefit from our challenges, our struggles, and, of course, our joys. The following questions can be considered. What were your symptoms of polio? Who noticed them? If you were examined by a doctor, what happened to you? What happened next? What aids were you given? Examples: crutches, braces, wheel chairs, etc. How old were you? How did polio affect your family? How were your studies affected? (if at all) What were some of your obstacles you had to face? What were some of the obstacles your family had to face? What activities did you miss out on? (if any) How did you feel at various times in your life with polio? Name 3 or 4 or more feelings and describe what was happening. These are just a few questions more to consider. You may have thought of others. The last questions are these: What blessings have happened to you? How have you grown spiritually? How have you grown as a human being?

PP104

WEIGHT LOSS USING A PROTEIN DIET – IS IT POSSIBLE AND HARMLESS IN WHEELCHAIR BOUND POLIO SURVIVORS?

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Introduction: Most patients who have relevant physical consequences after having contracted polio have a tendency to gain weight as a result of aging and inadequate physical activity. Physical activity and diets are often not even considered for fear that muscle strength could be lost as a result. In an open study without a control group, we considered the hypothesis of whether disabled polio survivors could achieve a relevant weight loss using a commercial meal-replacement protein diet and would such weight loss have a negative result. *Methods:* 24 polio survivors (18 women, 6 men) took part in the study. For 6 weeks the patients ate only meal-replacement products and drank at least 2 l per day. Every 2 weeks there was blood testing (creatinine kinase, uric acid and cholesterol) as well as recording of weight, blood pressure and subjective health. In addition each patient received both a nutritional and a psychological counseling session. (This study is already published). We were able to follow 17 of the 21 participants which had completed the study for 3 months later on. The results are presented. *Results/Conclusions:* Focusing on the wheel-chair users, all (#8) still had at least 5% less body weight than before; nearly all had lost additional kilograms after the study. There was no difference between men and women. Beside the successful effect regarding the weight loss there was a beneficial result affecting blood pressure, cholesterol and life satisfaction as well. This was an uncontrolled study with a small number of participants and thus with a low scientific standard; as there are very few studies focusing this problem, this approach may still be useful. Especially there were no major complications. Considering the good results further studies seem warranted. *Key point:* In this small study, even wheelchair users could achieve a relevant weight loss (>5%) and keep this weight for 3 months after the active diet without major negative effects.

PP105

IMPROVED ACTIVITY AND PARTICIPATION IN POLIOMYELITIS WITH ELBOW ORTHOSES: MORE 'RIGHT-TECH' THAN 'HIGH-TECH'. A CASE STUDY

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Introduction: This case study reports on a 65-year-old female with upper limb paralysis resulting from poliomyelitis at age 5. Both arms mainly present with grade 0 muscle strength, on the Medical Research Council (MRC) scale, from the glenohumeral joint distally. The only exceptions are when attempting to internally rotate the right arm at the shoulder (grade 1) and finger and thumb flexion and extension of the right hand only, which is preserved at grade 4. Bilateral custom elbow orthoses (EOs) were prescribed at age 10. The orthoses consist of 2.5 mm thick shells made from thermosetting plastic reinforced with cotton, steel joints placed medially and laterally to the elbow, and 4 leather straps. The elbow joint ratchet mechanisms lock at 40°, 75° and 95° of flexion, and release at full flexion. The user is able to flex and release the orthoses by the use of a 'shrug' motion with her upper body. The subject has used the EOs throughout her life and finds that they allow her to fulfill key activities of daily living including eating, drinking and toileting. A considerable recent difficulty has been replacing the ageing elbow joints. The original manufacturer no longer exists and modern alternatives have either proved insufficiently durable, or have required alternative operation techniques which have been unacceptable to the user. These difficulties reflect the nature of accommodating carefully developed and longstanding user strategies, and the high forces the components need to withstand. *Methods:* Function with and without orthoses was evaluated subjectively using the Disabilities of the Arm, Shoulder and Hand (DASH) questionnaire. *Results:* The DASH score without EOs was 73.33, and with EOs was 45. This represents a positive change in score of 28.33. Minimal clinically important difference has been reported as between 10.83 and 15. These results indicate that while the subject is considerably affected by her condition (mean DASH score in the healthy population has been reported as 10.10), definite improvement is achieved with EOs. Significant improvement in performance of activities and social participation are reported with custom elbow orthoses for an individual with upper limb paralysis resulting from poliomyelitis.

PP106

URINARY DYSFUNCTION AMONG POLIO AND POST-POLIO PATIENTS

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Introduction: Acute poliomyelitis is characterized by fever, malaise and pain. In few days patients can develop signs of acute lower motor neurons dysfunction as an asymmetrical flaccid paralysis. After a period of prolonged stability, 25% to 60% of polio survivors can develop new symptoms caused by a condition named post-polio syndrome (PPS). It has been noticed that the majority of patients affected from polio syndrome (PS) experience bladder symptoms with a prevalence being approximately twice as the control population, and higher in adults than children, suggesting

that these problems may be secondary to the decline of function experienced in the long run. Following these observations, we analyzed the prevalence of urinary symptoms among a population of PPS patients compared to PS patients. *Materials and Methods:* *Subjects:* An age-matched sample of PPS and PS patients recruited from the polio clinic at Malcesine, Verona. *Inclusion criteria:* Diagnosis of PPS according to the March of Dime criteria for the first group and previous poliomyelitis for the second group. *Exclusion criteria:* any coexisting condition affecting the urinary tract. *Rating scales:* The American Urological Association Symptom Index (AUA-SI) for men, the Urogenital Distress Inventory-6 (UDI-6) for women. *Results:* A total of 87 patients were analyzed; 66 met the inclusion criteria (32 men, 34 women; median age 59,4 for men, 60,58 for women). Seventy-eight percent of PPS women and 75% of PS women complained at least one urinary symptom; the prevalence among men was respectively 100% and 85%. Comparing PPS to PS women, there was no statistical difference between groups ($p=0,23$), but comparing PPS to PS men, the difference was statistically significant ($p=0,003$). Interestingly the majority of PPS patients referred that urinary symptoms appeared after the diagnosis of PPS. Incomplete bladder emptying was the most frequent symptom described among PPS men, urinary urgency among women. *Conclusions:* Urinary complaints are common in both PS and PPS patients, but, at least for men, PPS patient showed an increased prevalence of symptoms compared to PS patients, suggesting that PPS could represent a risk factor independent from age for the development of urinary dysfunction.

PP107

MORE THAN 50 YEARS FOLLOW-UP AFTER POLIO IN NORTHERN ITALY

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Introduction: Polio was in the 1950s a feared infection, causing a lifelong disability. 1953 a polio epidemic swept through Europe. Polio patients received comprehensive treatment and rehabilitation after the acute polio infection at Malcesine Hospital (MH) in northern Italy. After a stable period of at least 15 years some polio patients experience increasing paresis, pain and/or fatigue and might fulfill the criteria's for Post-Polio Syndrome (PPS). The aim of the study was to study age at polio infection, gender, initial symptoms, grade and localization of paresis, walking aids, length of the first recovery. Their actual medical situation was analyzed according to pain, fatigue, grade and localization of paresis, walking aids, concomitant diseases. The number of patients that fulfilled the criteria's for PPS was analyzed. *Methods:* MH is located in Val di Sogno in northern Italy. The activity with polio patients started 1952. Nowadays polio/PPS patients receive cycles of rehabilitation. The medical files from the recovery after acute polio 1952–1961 and from 2012 were studied. The patients that received cycles of rehabilitation in 2012 and received rehabilitation 1952–1961 were identified. PPS was diagnosed according to the criteria's of March of Dimes. The patients were divided into two groups, if they fulfilled the criteria's for PPS or not (NPPS). *Results:* 505 medical files were studied. 67 of 71 patients that received the first rehabilitation and cycles of rehabilitation 2012 at MH were included in the study. Mean age at polio infection was 18 months. The infection started mostly with fever. Asymmetric paresis of both legs were most common. Orthopedic shoes was followed by leg braces the most common orthopedic device. Mean time of the first in-hospital rehabilitation was 3 month. Forty-one percent fulfilled the criteria's for PPS. PPS was statistically more common in women. Pain was common in both PPS and NPPS. *Discussion:* Polio or infantile paresis caused in most cases asymmetric paraparesis. The first recovery was long. Forty-one percent fulfilled the criteria's for PPS. Mean time from acute polio to PPS was 35 years. PPS suffer from a more severe disability. To diagnose PPS correctly is of utmost importance.

PP108

CORRELATION OF ARM-SPAN AND BODY HEIGHT IN POST-POLIO PATIENT WITH MUSCLE PARALYSIS IN THE LOWER EXTREMITIES

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Introduction: One of the more important deformities caused by poliomyelitis is a slowing growth of the affected limb. This study presents the results of an anthropometric investigation of 24 patients with post-polio syndrome. *Subjects:* Twenty-four consecutive patients (mean age 64 years), with late effects of polio and weakness of muscles in one or both lower extremities referred to the Danish Society of Polio and Accident Victims (PTU) Rehabilitation Centre in Aarhus. *Methods:* The following anthropometric measurements were taken using standardized protocols: Body height and weight, and arm-span were assessed with a measuring tape. Handgrip of the right and left hand, and the circumferences of both thighs and calf's were obtained. The year of polio infection, and thus the age at infection was calculated. *Results:* The patients demonstrated a significant positive relationship between arm-span and body height ($r=0.86, p<0.01$), and the difference arm-span minus body height was negatively related to age at polio infection ($r=-0.44, p<0.05$). The relation between right and left handgrip strength was highly significant ($r=0.94, p<0.001$), and grip-strength was positive related to arm-span ($r=0.48, p<0.01$). *Conclusion:* Post-polio patients with muscle paresis in the lower extremities have a significant smaller body height than expected in relation to their arm-span. The differences increase with younger age at infection. Arm-span measurement is recommended to be included in future evaluation of post-polio subjects.

PP109

WHAT IS THE EVIDENCE FOR ANESTHESIA PROBLEMS IN POST-POLIO PATIENTS?

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Introduction: Multiple problems with anesthesia are self-reported by post-polio (PP) patients, such as excessive sleepiness, cognition problems and drug sensitivities. Various non-anesthesia publications have repeated this list of possible anesthesia problems. However, anesthesiologists are not familiar with these problems. Publication in a peer-review journal is considered the standard to confirm evidence in medicine. This abstract reports the published evidence for anesthesia problems in PP patients. *Methods:* The medical literature was searched via the United States' National Library of Medicine's PubMed data base of medical literature. Search term was "polio AND anesthesia." Papers which did not report clinical care/research were deleted. A spread sheet was used to organize found articles by year published, type of article, topic and geographic origin. Letters correcting or commenting on an article were compiled separately. *Results:* Twenty-two reports were available for analysis. There were 4 letters of comments or correction. Publication occurred from 1990-2013. Source countries were 11 and were world-wide. Topics were regional anesthesia (7), obstetric (OB) anesthesia (5), review of PPS changes in relation to anesthesia management (3), reports of postoperative complications (3), general anesthesia (2), anesthesia for Electro Convulsive Therapy (1), local anesthesia (1), dental anesthesia (1) and physiology of muscle relaxants in post-polio patients (1). No report documented excessive sleepiness, cognition problems and/or drug sensitivities. Acceptable published evidence is available for use of regional anesthesia and for OB anesthesia. No significant anesthesia problems were reported in these 2 areas. Placement of regional anesthesia blocks in PP patients with deviated spines is facilitated today by use of ultrasound. No patient having regional anesthesia

had worsening of neurologic status postoperatively. *Conclusions:* There is no published evidence for patients' complaints of excessive sleepiness, cognition problems and drug sensitivities. There is good evidence that regional anesthesia can be safely used for both surgery and OB anesthesia, if the patient's ventilatory status allows. Regional anesthesia is highly desirable, and PP patients can have access to this beneficial form of anesthesia. More studies of general anesthesia are needed to investigate the traditional patient complaints.

PP110

SELF-REPORTED IMPAIRMENTS, WALKING LIMITATIONS, FEAR OF FALLING AND THE ASSOCIATION WITH PHYSICAL ACTIVITY IN PERSONS WITH LATE EFFECTS OF POLIO

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Introduction: Persons with late effects of polio experience new symptoms or impairments decades after an acute paralytic poliomyelitis infection. Common impairments are muscle weakness, muscle fatigue, general fatigue, pain during activity and cold intolerance. The muscle weakness in the lower limbs often leads to reduced walking ability and is a risk factor for falls. As many as 50–84% of persons with late effects of polio report at least one fall per year and up to 95% reported fear of falling. The impairments following late effects of polio, the reduced walking ability, and the fear of falling can reduce the activity level, restrict perceived participation and lead to a sedentary lifestyle. The aim of this study was to determine the relationship between self-reported impairments, walking limitations, fear of falling and physical activity in 81 ambulatory persons with late effects of polio. *Main outcome measures:* Impairments was assessed by the Self-reported Impairments in Persons with late effects of Polio (SIPP), walking limitation was assessed by the Walking Impact Scale (Walk-12), fear of falling was assessed by the Falls Efficacy Scale – International (FES-I). Physical activity was assessed by the Physical Activity and Disability Survey (PADS) and by a pedometer. *Results:* The mean score for SIPP was 34% (SD 18%), for Walk-12 48% (SD 28%) and for FES-I 28 points (SD 9). The total scores in SIPP, Walk-12 and FES-I were significantly correlated with the number of steps ($r=-0.23$ to -0.32 , $p<0.05$). Only Walk-12 was significantly correlated with the sum of PADS ($r=-0.31$, $p<0.05$). Walk-12 and age explained 14% of the variance in the sum of PADS and FES-I explained 9% of the variance in number of steps per day. *Conclusions:* Self-reported impairments, walking limitations and fear of falling in ambulatory persons with mild to moderate late effects of polio can only explain the ability to be physically active to a small extent. Further studies are therefore needed to explore factors that are associated with the ability to be physically active in this group of people.

PP111

TRANSCRANIAL DIRECT CURRENT STIMULATION (tDCS) FOR SLEEP DISTURBANCES AND FATIGUE IN PATIENTS WITH POST-POLIO SYNDROME

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Purpose: Post-polio syndrome develops about 20–40 years after acute paralytic poliomyelitis, and manifests with progressively

deteriorating muscle strength and endurance. Here, we assessed whether transcranial direct current stimulation (tDCS) improves sleep and fatigue symptoms in patients with post-polio syndrome. *Methods:* We enrolled 32 patients with a diagnosis of post-polio syndrome. tDCS (1.5 mA, 15 min) was delivered by a direct current stimulator connected to 3 electrodes: two anodal electrodes on the scalp over the right and left pre-motor cortex and the other above the left shoulder (cathode). 16 patients received anodal tDCS and the remainder sham tDCS. We evaluated changes induced by tDCS (daily for 5 days a week, for 3 weeks) on clinical scales (Short Form Health Survey [SF-36], Piper Fatigue Scale [PFS], Fatigue Severity Scale [FSS], 101-Point Numerical Rating [PNR-101], Hamilton Rating Scale for Depression [HRSD], Pittsburgh Sleep Quality Index [PSQI]) at baseline (T0) and 3 weeks later (T1). *Results:* At T1 SF-36 sub-items physical functioning, role physical, vitality, social functioning and role emotional improved significantly more in patients who received tDCS ($p<0.01$) than in sham-treated patients. Also, PSQI scores improved more in treated patients ($p<0.05$, two-way ANOVA with "stimulation" and "time" as factors: $p<0.01$). tDCS-induced benefits were more pronounced in patients who were younger at primary infection ($p<0.05$). *Conclusion:* Anodal tDCS over the pre-motor areas for fifteen days improved sleep and fatigue symptoms in patients with post-polio syndrome. tDCS could be a non-invasive and valuable new tool for managing post-polio patients.

PP112

POST-POLIO SYNDROME AND MUSCLES PAIN: OBSERVATION AMONG 2,985 PATIENTS

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Introduction: Polio survivors in Israel are estimated at 10,000. I want to introduce our experience with polio survivors who were seen in our Clinic in "Assaf Haroffe" Medical Center-Israel. *Method:* A retrospective study of polio survivors seen in the last 20 years. *Results:* 2,985 patients (1,658 women and 1,327 men), with a mean age of 62 years \pm 14.3 (range 9-82) consulted our hospital. 1,015 (34%) of the patients were diagnosed with post-polio syndrome (PPS). The other patients visited our clinic for other reasons, such as common musculoskeletal problems, trauma or only for consultation. In polio survivors with PPS the complaints were muscle pain (1,005 subjects), fatigue (784) and new muscle weakness (800) and new objective new paralysis (14). PPS criteria were the complaints and findings of muscle tenderness and fasciculations on physical examination. Muscle pain, muscle weakness and muscle tenderness were often combined. *Conclusion:* These polio survivors often experienced functional worsening. The worsening is due to aging, common musculoskeletal problems and PPS. Due to the combined finding of muscle pain, muscle weakness and muscles tenderness we have the impression that the major problem of PPS are the muscles.

PP113

ASSESSMENTS TO EVALUATE ACTIVITY AND PARTICIPATION OF POLIO SURVIVORS

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Introduction: To correctly detect diseases and the following consequences for patients as well as to express therapy standards, measurement instruments to assess the state of health as well as special factors describing activity and participation of the patient gain clinical and scientific relevance. Here, the common language is expressed in ICF. It becomes possible to measure the need and efficiency of individual treatment options with the development

of a summing up assessment instrument aiming key aspects of post-polio patients for medical staff as well as for sponsors. Aim of the actual literature investigation is the preparation of core set development. *Method:* Basis of the investigation was the scientific platform PubMed containing publications of the past 50 years with the key words: Poliomyelitis, Post-Polio Syndrome, Post-Poliomyelitis Syndrome and Previous Polio connected with impairment, disability, pain, fatigue, endurance as well as muscle weakness. The found publications were sorted regarding their relevance concerning the evaluation of assessment methods. Next, the as relevant considered studies were summarized and based on this assigned to the appropriate ICF category. *Results:* 425 publications were detected using PubMed investigation. Just 85 articles were classified as relevant. 31 of the relevant articles were statistically important and were evaluated concerning their scientific validity by two reviewers. Scores for individual life areas illustrated in different studies were calculated from the corresponding sum of points. Therefore, the sum of the assessment points with regard to their statistical significance was generated followed by a division by the number of articles evaluating the areas. Therefore, the relevance of all 7 life areas (mobility, pain, social life, bodily and emotional function, life quality and activities of daily life) of the post-polio syndrome evaluation with scores account higher than 7 was asserted. Hence, they should be included in the core set recommendation. All in all, 22 categories of body function, 15 of body structure, 30 components of activity and participation as well as 15 environmental factors resulted in the core set. Next this core set will be verified in 3 German institutions with collaboration of physiotherapists, occupational therapists and rehabilitation physicians on patients with post-polio syndrome.

PP114

POST-POLIO SYNDROME – CLINICAL, DEMOGRAPHIC AND SEVERITY EVALUATION AMONG POLIO SURVIVORS IN JERUSALEM

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Objective: To determine the medical, demographic and socioeconomic parameters associated with the development of post-polio syndrome (PPS) among polio survivors in Jerusalem. *Materials and methods:* A prospective cohort study of polio patients attending the post-polio clinic in Hadassah Medical center in Jerusalem. Demographic, medical, social, and functional data were recorded using a particular questionnaire adjusted to the polio population. The existence of PPS was diagnosed according to the March and Dimes criteria, the severity of PPS had been determined using the index of PPS score (IPPS). *Results:* Among 194 polio patients screened, 154 (79%) were diagnosed as suffering from PPS, among them 78 (51%) were men. Polio patients with PPS had significantly more difficulties in walking outdoor and in ADL functions ($p=0.042$ and $p=0.007$, respectively). Demographic and clinical parameters were identical between polio patients with or without PPS and the only significant risk factors to develop PPS were lower education and higher BMI. The total IPPS score was significantly correlated with health, ADL and mobility parameters. Polio survivors with lower education or women suffer from more severe polio sequelae. Polio survivors who still work suffered less significant polio sequelae. Implications/impact on rehabilitation. The prevalence of PPS in our population was among the highest reported. Polio survivors with PPS show significant difficulties in ambulation and in ADL functions in comparison with polio survivors without PPS and the general population. These findings promote the need for specific rehabilitation programs for polio survivors in order to maintain their function and to prevent further deterioration due to PPS.

PP115

WHO AM I? FEMALE POLIO SURVIVORS PERCEPTIONS OF IDEAL AND LIMITED SELF

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Identities are an individual's responses to the question 'Who am I?' as components of a composite sense of self. This can include past, present, and future levels of identity. Biological, psychological, and social changes in later life have the potential to impact on an individual's sense of self. The aim of this research was a comparison between participants' ideal selves and their collective identities. *Method:* 8 semi structured interviewed were analysed utilising constant comparison approach analysis. These interviews were conducted as part of the British Polio Heritage project to reflect a 'Celebration of Life'. The average age of participants at the time of interview was 60.14 years (range 54–72 years). All had contracted polio between the years of 1953–1958. *Findings and Conclusion:* Our research found that participants' collective identities were evident in the theme 'a limited self'. A limited self was influenced by medical, family and societal attitudes that influenced the types of activities that were undertaken such as employment, educational opportunities and sporting activities. Participants' limited selves became less noticeable when they overcame societal barriers, in pursuit of their ideal selves, particularly for those who were managing post-polio syndrome. An interagency response is needed that involves educating society about disability issues. *Key points:* An interagency approach is needed to educate about disability issues Health care professionals need to ensure that rehabilitation programmes enable polio survivors to pursue their ideal self.

PP116

SOCIAL CONSEQUENCES AMONG 4,267 PERSONS, WHO CONTRACTED POLIOMYELITIS IN COPENHAGEN, DENMARK 1920–1954. FOLLOW-UP FOR MORE THAN 60 YEARS

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Background: In Denmark it is estimated that 12,000 persons still live after surviving the polio epidemics in the 1940's and 1950's. The full long-term consequences of poliomyelitis still remain to be established. Earlier studies have been carried out among polio survivors seeking healthcare systems; these are selected study populations that may result in an overestimation of negative consequences. *Aim:* To estimate social consequences of poliomyelitis in a cohort of Danish polio patients admitted to hospital for poliomyelitis in 1920–1954. *Methods:* A cohort study including 4,267 persons hospitalised for poliomyelitis in the period 1920 to 1954 in Copenhagen, Denmark, and 17,015 age and gender-matched Danes as controls. As all official Danish registers use the same Personal Identification Number: a unique number allocated to every Danish resident, it was possible to trace the cohorts through all the registers. The exposed (poliomyelitis) cohort and the unexposed (control) cohort were followed using data on social transfer incomes, pensions, income, education and occupation obtained from Statistic Denmark, which for the period 1980 to 2013 contains annually updated data socioeconomic factors for the entire Danish population. *Results:* The result of this cohort study will be presented.

PP117

LONG-TERM MORBIDITY AMONG 4,267 PERSONS, WHO CONTRACTED POLIOMYELITIS IN COPENHAGEN, DENMARK 1920–1954. FOLLOW-UP FOR MORE THAN 60 YEARS

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Background: In Denmark it is estimated that 12,000 persons still live after surviving the polio epidemics in the 1940's and 1950's. The full long-term consequences of poliomyelitis still remain to be established. Earlier studies have been carried out among polio survivors seeking healthcare systems; these are selected study populations that may result in an overestimation of negative consequences. **Aim:** To estimate the long-term morbidity of poliomyelitis in a cohort of Danish polio patients admitted to hospital for poliomyelitis in 1920–1954. **Methods:** A cohort study including 4,267 persons hospitalised for poliomyelitis in the period 1920 to 1954 in Copenhagen, Denmark, and controls of 17,015 age- and gender-matched Danes. The cohorts were traced in various official registers – all registers using the same Personal Identification Number: a unique number allocated to every Danish resident. The exposed (poliomyelitis) cohort and the unexposed (control) cohort were followed up for hospitalisation including psychiatric diseases, from 1977 to 2013 in the Danish Hospital Discharge Register and the Danish Psychiatric Central Research Register. To examine the burden of diseases not requiring hospitalization information on usage of medication will be obtained for the period 1996–2013 from the Danish Prescription Drug Registry. **Results:** The results of this cohort study will be presented.

PP118

LOW PREVALENCE OF CHRONIC VENTILATORY INSUFFICIENCY IN A COHORT OF POLIO SURVIVORS

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Introduction: In aging polio survivors chronic ventilatory insufficiency may develop insidiously and remain unrecognized. The aim of the study was to determine the prevalence of chronic ventilatory insufficiency in polio survivors of a longitudinally followed cohort of patients with late onset sequelae of poliomyelitis. **Methods:** First, 145 patients were screened with a questionnaire on sleep disordered breathing, and with handheld spirometry. If results of the questionnaire were suspect or lung function was restricted, patients were referred to a center for home mechanical ventilation for further assessment. **Results:** Three of the 145 patients were already on nocturnal home ventilation because of nocturnal hypoventilation, two of whom had been mechanically ventilated during acute polio. These 3 patients were excluded from further screening. Screening was positive in 39 patients. While 16 of them declined referral, no new cases of chronic ventilatory insufficiency were identified in the 23 patients who attended a center for home mechanical ventilation. **Conclusion:** In this cohort of polio survivors the prevalence of chronic ventilatory insufficiency was low and new cases were not found. Notwithstanding these findings, medical professionals should be aware of chronic ventilatory

insufficiency as a possible late consequence of polio, especially in polio survivors who had respiratory involvement during acute polio.

PP119

THE DANISH VERSION OF THE SELF-REPORTED IMPAIRMENTS IN PERSONS WITH LATE EFFECTS OF POLIO (SIPP)

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Background and aim: The Self-Reported Impairments in Persons with Late Effects of Polio (SIPP) is a Swedish new rating scale developed to measure self-perceived impairments in persons with prior polio. The aim of this study was to create a linguistic validated Danish version of the SIPP. **Method:** The Swedish version of SIPP was translated into Danish by two native Danes understanding Swedish. The two translations were given to a third Dane, and differences were discussed reaching agreement on verbal expressions. This version was then translated from Danish into Swedish by a native Swede. The forward-backward translation was compared to the original Swedish version together with the original developer and consensus was reached. Finally a cognitive debriefing was done by giving the Danish version to 6 persons with late effects of polio and who were asked to comment on the rating scale. **Results:** There were no great differences between the two first Danish versions of SIPP. Only a few words were translated differently and agreement was easily reached. The backward translation into Swedish resulted in a discussion of 3 issues: the translation and understanding of “lite grann” (to some degree), “uträttbarhet” (fatigue) and “andingsproblemer” (problems with respiration), but it caused only little discussion. Given to persons with late effect of polio revealed comments on some items they thought had been left out, and some comments and problems of understanding that the questions concerned only “two weeks earlier”. The items suggested to be included were incontinence, questions on daily activities and problems due to overload. As the aim was to translate the Swedish version and not to create a new rating scale these issues were omitted. In addition, issues not related to impairments were also omitted. **Conclusion:** SIPP was translated and adapted into Danish using a forward-backward translation and monolingual test, which produced a Danish version that can be used to assess self-perceived impairments in Danish persons with prior polio. **Key point:** The Danish version of SIPP parallels the original Swedish version.

PP120

THE EFFECT OF TREATMENT WITH IMMUNOGLOBULIN ON NOCICEPTIVE AND NEUROPATHIC PAIN IN POST-POLIO PATIENTS. THREE CASE REPORTS

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Introduction: Pain is a common symptom in the post-polio syndrome. Previous studies have shown an effect on pain in patients receiving intravenous immunoglobulin. The aim of this study was to analyze the effect of intravenous immunoglobulin on neuropathic and nociceptive pain in 3 patients with post-polio syndrome. **Methods:** Three patients with post-polio syndrome and pain who received treatment with 90 g intravenous immunoglobuline are described in this case report. **Results:** Before treatment, one of the patients had pure neuropathic pain and the other two had a combination of neuropathic and nociceptive pain. There was no effect on pain in the patient with pure neuropathic pain and only effect on the nociceptive pain in the patients with a combination of neuropathic and

nociceptive pain. The present study indicates that the effect of immunoglobuline treatment is limited to nociceptive pain, while there is no effect on neuropathic pain. This leads to increased knowledge in characterization of responders of immunoglobuline treatment. The classification of pain in post-polio patients is of great importance, since this case report shows that treatment with immunoglobuline had effect on nociceptive but not neuropathic pain.

PP121

INTERNAL CONSISTENCY AND TEST-RETEST RELIABILITY OF THREE FATIGUE RATING SCALES IN PERSONS WITH LATE EFFECTS OF POLIO

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Background: General fatigue is a commonly reported impairment among persons with late effects of polio. Fatigue can impact on the ability to perform daily activities, on perceived participation and lead to reduced life satisfaction. To be able to assess changes over time in reported fatigue and to evaluate the effects of different interventions, reliable outcome measures are needed. **Objective:** The aim of this study was to evaluate the internal consistency and test-retest reliability of 3 fatigue rating scales in persons with late effects of polio. **Methods:** A postal survey was administered to 77 persons with clinically and EMG verified late effects of polio. Fatigue was assessed with the following rating scales: the Fatigue Severity Scale (FSS; consisting of 9 items), the Fatigue Impact Scale (FIS; consisting of 40 items) and the Multidimensional Fatigue Inventory (MFI-20; consisting of 20 items divided into 5 subscales: general fatigue, physical fatigue, mental fatigue, reduced activity and reduced motivation). After 3 weeks the responders received a second survey. Reliability was assessed as internal consistency reliability (Cronbachs alfa) and test-retest reliability (Intraclass Correlation Coefficient, ICC). **Results:** Sixty-one persons (28 men and 33 women; mean age 68 years and mean time since onset of late effects of polio 18 years) responded to the survey. Sixteen participants were working and 40 were retired. About 40% could walk more than 1000 meters and the remaining walked less than 1000 meters. The internal consistency reliability (Cronbachs alfa) was high (>0.94) for all 3 rating scales. The test-retest reliability (ICC for single measures) for FIS was 0.72 (95% CI 0.62 to 0.76), for FSS 0.59 (95% CI 0.40 to 0.73), and for the MFI subscales ICC ranged from 0.33 (physical fatigue) to 0.63 (mental fatigue). **Conclusions:** This study shows that these rating scales can be used to assess fatigue in persons with late effects of polio, but the ICC values indicate that the reliability varies considerably between the scales. Further psychometric analyses of these scales are needed before definite recommendations can be made about which scale to choose to assess fatigue in persons with late effects of polio.

PP122

UNDERWATER SWIMMING EXERCISES FOR POLIO PATIENTS

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Introduction: Many polio patients experience pain, fatigue and reduced respiratory capacity later in life. This study was planned as a pilot study with the aim to evaluate the effect of respiratory training for polio patients by training underwater swimming with techniques from elite diving. **Methods:** Twelve polio patients, yielding no results by conventional training, volunteered for the project. The training comprised two 45 min sessions: one on land and one in water. The land session focused on practicing relaxation, mindfulness, consciousness of respiratory function, breath holding and respiratory

muscle training. The exercises and experiences from this session were then used in the water session to train underwater swimming. Training was conducted twice a week for 3 months. Prior to, and after 3 months of training, the following measurements were done: Pulse, blood pressure, FEV1, FEV6, pain (VAS), sleep tendency (ESS), stress (stress test), quality of life (SF-36), and tiredness (MFI-20). **Results:** Eleven patients completed the training program. Significant improvement ($p < 0.05$) was found for pain (VAS and physical pain aspect of SF-36), stress, and for physical tiredness and motivation in the MFI-20. Tendency to fall asleep also improved with $p = 0.05$. Pulse, blood pressure, FEV1 and FEV6 changed only very little, and with no general trend. **Conclusions:** This pilot study indicates that respiratory exercises used for the training of diving can be beneficial for polio patients in terms of quality of life, pain, fatigue, stress and sleep tendency. **Acknowledgements:** the training has been carried out with assistance from the world champion in free style diving Stig Åvall Severinsen, Breatheology®.

PP123

REHABILITATION FOR PERSONS WITH POST-POLIO SYNDROME AT AKADEMISKA HOSPITAL, UPPSALA, SWEDEN

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Background: Post-polio syndrome (PPS) counts as the most common neuromuscular disease in Sweden. Since the 1950, persons in Sweden are vaccinated against polio, and as the result polio was eradicated in our country. However, there were people who fell ill before the vaccine was available and who later on developed PPS. In addition, polio survivors migrate to Sweden from countries where polio epidemics occurred more recently or still exist. In Sweden it is estimated that 18,000 to 20,000 people have had polio. The Rehabilitation Medicine Clinic of the Akademiska Hospital provides rehabilitation for people with polio residuals. The rehabilitation consists of several parts, including an outpatient clinic for assessment and counseling, pool training to a limited extent, a post-polio course and, where appropriate day rehabilitation. Rehabilitation takes place intradisciplinary by a team consisting of an occupational therapist, physiotherapist, social worker, nurse and doctor. The goal of rehabilitation is that the individual takes responsibility for a lifestyle change and thus is able to adequately handle various daily activities and the long-term achievement of the targets within the family, at work and at play. Thereby achieving good participation and life satisfaction. **Objective:** To describe working with people with post-polio syndrome at our Rehabilitation Medicine clinic. **Method:** Description of the activities of the Rehabilitation Medicine clinic. **Results:** Our results regarding the number of patients and further treatment will be reported as well as the evaluations from the post-polio courses that were organized.

PP124

IMAGING OF THE POST-POLIO AFFECTED MUSCLE ARCHITECTURE WITH DIFFUSION TENSOR MRI: A PILOT STUDY

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Introduction: In post-polio syndrome progression of muscle weakness, is usually assessed with strength measures, which are not very sensitive to change. Therefore, there is a great need for better methods

to assess disease progression. Normal MRI only allows for a dichotomous characterization: muscles are normal, or show atrophy and/or replacement by fat without giving information about the presence of remaining muscle architecture. With the use of the MRI technique Diffusion Tensor Imaging (DTI) in combination with tractography, it is possible to quantify and visualize muscle status and architecture. We therefore performed a feasibility study to show DTI can provide new *in vivo* insights in disease progression and muscle plasticity. *Methods:* Both upper legs of a male healthy volunteer and a post-polio patient were measured using a 3T Philips Intera scanner with a 16 channel coil. Three acquisitions were performed: Anatomical T1 and T2 weighted imaging and diffusion tensor imaging (DTI). The data was acquired in 3 40 slice stacks with a 5 slice overlap and a FOV of 400×400 mm² and slice thickness of 4 mm. Total scan time was 45 min. From the DTI images the following parameters could be derived: eigenvalues (λ_1 , λ_2 and λ_3), the mean diffusivity (MD) and the fractional anisotropy (FA). Whole volume fiber tractography was performed per segmented compartment. Tracking stopped at an angle change of 15 degrees per 0.2 voxel integration step and tracts had a minimal length of 50 mm. *Results:* DTI parameters within fat infiltrated muscles were close to equal with those in sub-cutaneous fat tissue, which was in agreement with the anatomical T1 and T2 weighed images. However DTI tractography showed well-organized muscle fiber architecture within heavily fat-infiltrated muscles, the same as in healthy muscles. *Conclusion:* Our DTI acquisition and post-processing strategy showed to be feasible and revealed well-organized muscle structure within heavily affected muscle tissue beyond the scope of anatomical MRI images. These preliminary findings indicate that DTI may be useful to accurately assess muscle integrity in patients with post-polio syndrome. For clinical application, further investigations in larger groups of patients are needed to assess reproducibility and sensitivity to change.

PP125

FATIGUE AND QUALITY OF LIFE IN PEOPLE WITH PPS

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Introduction: The aims of research conducted by Walton Centre NHS Foundation Trust (Liverpool, UK) include the development of validated self-report measures for fatigue and needs based quality of life and validation of existing generic measures. The measures developed and the data collected at 4 time points over 27 months also contain valuable information on the symptoms and impact of post-polio syndrome (PPS) among the study population. The work reported here summarises the preliminary analysis of this data. *Method:* Volunteers from across the UK who met the standard criteria for a diagnosis of PPS completed questionnaire packs at months 0, 9, 18 and 27. *Results:* The study population consisted of 68% women and 32% men between the ages of 50 and 90, mostly retired. The number of participants at baseline was 319 with a high retention of 207 at 27 months. Initial results indicate that fatigue in PPS is not related to age, a finding similar to fatigue in other conditions such as multiple sclerosis. Fatigue was moderately inversely correlated with quality of life as measured by the WHOQoL-Bref questionnaire and also moderately correlated with anxiety and depression as measured by the Hospital Anxiety and Depression Scale, and with pain scored on a visual analogue scale (VAS). Self-reported pain levels were 30% higher on average for women than men. 18% of women scored a pain level of 9 compared to 3% of men; 18% of men scored a pain level of zero compared to 2% of women. Measured anxiety levels for women were 20% higher than for men though there was no significant difference in depression. Women also reported higher levels of fatigue than men; the difference was small but statistically significant. These differences were consistent over the 27 month study. *Conclusions and Key Points:* These results aid the understanding of the impact of PPS and how reported symptoms vary with age and gender. This study

indicates that fatigue in PPS does not vary with age but does correlate with quality of life, pain, anxiety and depression. The reported levels of pain and anxiety were higher in women than men.

PP126

CARE OF POST-POLIO SYNDROME AFFECTED PEOPLE

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Our experience and observance of nursing care provided by our clinic in the treatment of over 500 patients with post-polio syndrome of all age groups and with a wide variety in paralysis. Nursing care consisted of 1) Individual assistance with paralysis of the upper and lower extremities (patient lifter, electrical bed, slide board, roll board). 2) All rooms are barrier-free, and equipped handicapped accessible bathrooms. 3) Instructions for functionally appropriate use in stationary polio assessment 4) Isokinetic therapy monitoring, equitable, activating care with Motomed and Motomed Letto (including weekends). 5) Advice on resource preservation. 6) Polygraphy equipment – to check breathing due to respiratory muscle weakness.

PP127

THE REHABILITATION PLAN CAN FACILITATE ADAPTATION IN PEOPLE WITH LATE EFFECTS OF POLIO

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Introduction: An active engagement in forming a rehabilitation plan is important in the process of change during rehabilitation in general and for clients with late effects of polio. However, little is known how the rehabilitation plan influences clients during a rehabilitation process and the outcome of rehabilitation. The aim of this study was to explore how the rehabilitation plan influences the rehabilitation process and outcome in clients with late effects of polio undergoing rehabilitation. *Methods:* Four women and two men with late effects of polio were interviewed before, directly after, and at follow-up after discharge from an interdisciplinary rehabilitation period. Data were analyzed according to the constant comparative method of grounded theory. *Results:* The results formed one core category: “The same starting point but different rehabilitation processes”. Before rehabilitation, all clients experienced a similar starting point: a naïve understanding of rehabilitation. This was followed by two separate processes: i) clients experienced their rehabilitation as either being a mutually shared process leading to a continuous adaptation that enhanced activity and participation, or ii) as a staff directed process not leading to a substantial change. Goals set by staff directed clients focused on impairments whereas mutually shared clients set goals that focused on activity and participation. *Conclusion:* A mutually shared rehabilitation process can facilitate the adaptation process and may lead to rehabilitation outcomes that are more individually targeted and focusing on the clients overall disability. Knowledge of the differences in the goal-setting process may support staff and clients towards a more holistic view of rehabilitation for clients with late effects of polio.

PP128

PREVALENCE OF POST-POLIO SYNDROME IN THE VALENCIAN COMMUNITY (SPAIN)

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Introduction: We consider it relevant to value the long-term evolution of patients who had polio in the past, to identify neurological worsening. **Aims:** To establish the prevalence of the post-polio syndrome (PPS) in our geographical area, to define symptomatology of neurological worsening and useful complementary tests. **Material and Methods:** Cross-sectional prospective and descriptive study of cases and controls. Our study population consisted of 80 cases with complaints of physical deterioration. Forty percent of the study group (32 patients) had a clinical diagnosis of PPS. The control group consisted of 41 patients. We conducted anamnesis, clinical examination, radiology, blood analysis, neurophysiological studies, respiratory function tests and scales to assess the degree of residual involvement and quality of life. **Results:** The average age was 44.5 ± 9.5 years, with a feminine predominance (52.5%). The age of infection was 1.6 ± 2.1 years, with an average period of 38 years since the acute polio and a stability period following recovery of 28.8 years. Orthopaedic affection: Equinus foot were associated with varus or valgus deformity (29.3%). Knee instability (31.8%) was the most frequent observation, affecting gait in 81% of patients. 60% presented with scoliosis, and only 25%, had an abnormal sagittal axis with severe kyphosis, flat back or hyperlordosis. Most frequent symptoms were a major tiredness with daily activity (63.8%), muscle or joint pain (65%) and loss of strength (58%). The studies of pulmonary function showed a decrease in peak expiratory flow ($70.8 \pm 44\%$), a decrease in maximal expiratory pressure ($77 \pm 55\%$) and an increase in residual volume ($143 \pm 70\%$). When patients presented with scoliosis/kyphosis a decrease appeared in respiratory capacity (80.6%). The EMG detected moderate spontaneous activity, with abnormal pattern. The study of neuromuscular transmission revealed a significant increase in percentage of affected plates. **Conclusions:** 1) Although most of patients developed orthopaedic problems, only 10% of them presented with new neurological problems, which rose to 40% among the patients who reported physical deterioration. 2) The perception of loss of strength and the triad of new weakness, weariness and functional loss correlated with PPS. 3) The differences in percentage of affected plates may contribute to clinical diagnosis of presumption. 4) Only the highest recovery after the polio infection showed a significant relationship as a risk factor.

PP129

CYTOKINE LEVELS AND ASSOCIATIONS WITH PHYSICAL DECLINE OVER 10 YEARS IN POST-POLIO SYNDROME

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Background: Several studies have reported elevated cytokine levels in peripheral blood samples and cerebrospinal fluid of patients with post-polio syndrome (PPS) indicative of a chronic inflammatory process in the central nervous system. Studies differed with respect to the cytokines that were investigated, storage of samples and analysing techniques. **Aim:** To investigate cytokine levels in peripheral blood of patients with PPS; and to investigate associations between cytokine levels and longitudinal decline in strength and physical functioning. **Methods:** In a cohort of 48 patients with PPS and EMG documented transmission abnormalities in a symptomatic quadriceps muscle we

reassessed muscle strength, walking capacity and physical functioning 10 years after baseline measurements. At follow-up we collected peripheral blood samples for EDTA plasma, which were immediately stored at -80°C . With Luminex we analysed a broad panel of 12 cytokines in all patients and compared these with a reference-sample of 18 controls matched for age and gender distribution. Associations between cytokine levels and decline in strength and functioning were analysed. **Results:** Circulating TNF- α , IL-6, IL-8, IL-18 and leptin were significantly higher, and IL-1RA trendwise, in PPS patients than in controls. No significant increases were found for IL-1 α , IL-1 β , IL-10, IL-13, IL-17 and IFN- γ . Levels of TNF- α , IL-6, IL-8, IL-1RA and IL-18 were interrelated. In the PPS subjects no associations were found between cytokine levels and decline in quadriceps strength, walking capacity or physical functioning. **Conclusion:** The elevated cytokines and their high intercorrelations confirm that a chronic inflammatory process is manifest in PPS. Although we did not collect baseline samples of cytokines, the lack of any association between cytokine levels and decline in physical parameters over 10 years, suggests that chronic inflammation does not influence the course of decline in PPS.

PP130

A REVIEW OF MAXIMUM VOLUNTARY ISOMETRIC CONTRACTION IN POLIO SURVIVORS OVER FOUR TO TWELVE YEARS

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Information regarding the rate of decline in muscle strength experienced by polio survivors is of concern to both health care providers and polio survivors. Evaluation of the changes in muscle strength utilising sensitive assessment methods in large cohorts is required. Polio survivors attending Beaumont Hospital have had 5 upper and 4 lower limb muscle groups assessed annually or bi-annually, using fixed dynamometry, since 1999. At the end of 2012, 65 of 178 patients had MVIC data, which had been accumulated over at least 4 and up to 12 years. This data was analysed using linear mixed-effects regression. In addition, summed upper and lower limb scores were calculated and analysed and the rate of change in limbs most affected by Polio was assessed. Sixty-five patients (66% females) were included with a mean age of 55.4 (SD 8.3) years at the first and 61.6 (SD 8.1) years at the final test. There was a median of 6 years between the first and last tests with a median of 5 tests completed. Statistically significant changes in hip flexion (-1.6% per year, $p=0.02$) and elbow flexion (-1.7% per year, $p=0.004$) were identified. Changes in other tested movements including knee extension (-0.9% per year, $p=0.3$) and shoulder abduction (-1.1% per year, $p=0.08$) were not statistically significant. The change identified in the upper limb summed score was -1.8% per year ($p=0.003$), while the lower limb summed score declined at a rate of 1.2% per year ($p=0.08$). The more affected lower limbs declined at a rate of 1.8% per year ($p=0.02$), while the more affected upper limbs declined at 1.4% per year ($p=0.2$). The study indicated a slow decline in muscle strength in Polio survivors, consistent with previous reports (Stolwijk-Swuste et al., 2010). The identified rates of decline are similar to that identified in healthy ageing. Further studies are required including comparison to healthy controls and larger cohorts.

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