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Polio Oz News

June 2017 - Winter Edition

How To Exercise If You Are Living With Post Polio Syndrome

By Stephen Pate

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Stephen Pate on NuStep T4r (photo NJN Network)

If you have Post Polio Syndrome (PPS), it's vital to exercise moderately every second day to keep the muscles we have and avoid obesity, diabetes, stroke and heart disease. Exercise also helps us accomplish more of those activities of daily living and can improve how we feel.

Why Exercise?

While it seems obvious, many of us with Post Polio Syndrome face enough weakness, fatigue and pain every day to make exercise seem impossible. We've tried exercise before and many develop an attitude of learned helplessness.

Thus, we rely more and more on assistive aids like wheelchairs and scooters. Lack of physical activity contributes to weight gain which makes things worse and we become even more deconditioned physically. It's a negative spiral we need to fight against.

I'll try to give you some practical suggestions that have worked for me, along with some that haven't. And I'll outline how I did recover some ability with the NuStep exercise machine. As a

precaution, I waited until I had 2 years of experience with the NuStep before recommending it, notwithstanding most hospitals use it as standard rehab equipment.

Exercise is one of the standard PPS treatments, along with rest, diet, energy conservation, environment adaptation. It's also one of the hardest things to do. The Mayo Clinic sums up the exercise prescription like this:

"Physical therapy: Your doctor or therapist may prescribe exercises for you that strengthen your muscles without you experiencing muscle fatigue. These usually include less strenuous activities, such as swimming or water aerobics, that you perform every other day at a relaxed pace.

Exercising to maintain fitness is important, but be cautious in your exercise routine and daily activities. Avoid overusing your muscles and joints and attempting to exercise beyond the point of pain or fatigue. Otherwise you may need significant rest to regain your strength." www.mayoclinic.org/diseases-conditions/post-polio-syndrome/basics/treatment/con-20021725

So, the gist is get some exercise – maybe swimming or water aerobics – every 2nd day but don't do too much or you'll be in trouble.

I've had PPS for 18 years and exercise is the bane of my existence. How do I get enough exercise without making things worse?

I used to hate exercise as part of the post polio prescription. How can I exercise if I can't walk, or walk very far? That question is part of the learned helplessness that can go with any disability.

Some medical professionals look at us on crutches or in wheelchairs and tell us to go easy. So, we assume the part of being helpless about our physical health. That's deadly.

There is plenty of published evidence to show people with post polio need and thrive on regular and moderate aerobic exercise. Strength training exercises for post polio are not recommended as they may damage weakened muscles.

(cont'd P3)

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Polio

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Towards

of

year, we held

end

the



Dr John Tierney OAM President

Australia AGM in Canberra, giving the whole Board the opportunity to participate in our annual "Walk with Me" activity at Parliament

House in Canberra, with MPs joining in. This was both a profile and fund raising exercise around the national parliament. Combined with the other *Walk with Me* event in Brisbane, over \$16,000 was raised in 2016 for Polio Australia.

Given this great success, we plan to do the same again in 2017, and we invite you to join us on Thursday 30th November at 1:00 pm at Parliament House for a walk / ride / scoot around the parliament and have a chance to lobby the MPs on behalf of polio survivors.

The Polio Australia lobbying team will also be in Canberra on the 15th of June to lobby for financial support for the needs of polio This year, Gillian survivors. Thomas, Mary-ann Liethof, and myself will be joined by Michael Queensland Powell, а Polio Australia Board member and the CEO of Spinal Life Australia (SLA).

As well as meeting with our Parliamentary Patrons, we are planning to meet with the Minister for Health, The Hon Greg Hunt MP, to advance our funding request for a program to support the training of health professionals in understanding and caring for the polio body.

These proposed Clinical Practice
Workshops would be based on
Polio Australia's highly successful
program trialed a year ago in
northern Sydney in partnership

with Rotary District 9685. This initiative was discussed directly with Minister Hunt last March by Mary-ann, Fran Henke and Dr Margaret Cooper, and received a positive response. Hopefully, our June follow up meeting will lead to funding. Fingers crossed.

In earlier editions of Polio Oz News, I have reported on how Polio Australia and SLA have been exploring how the two organisations could develop a productive partnership support our polio survivors. I am delighted to report that the Board of SLA have now agreed Polio to fund Australia \$100,000 dollars pa for the next two years, with a focus on developing self-sustaining funding strategies into the future.

This will enhance some of our existing fund-raising programs such as *Walk with Me*, Rotary links, and our new Bequest program. But we also plan to tap new sources such as philanthropic organisations and corporate sponsorship. This developing partnership with SLA is, indeed, a most exciting development.

The SLA funding begins on the 1st of July, but in the meantime Polio Australia has to make budget for 2016–2017. This now looks possible because of some excellent fund-raising work by member, our Board Gary Newton, who secured for us a philanthropic verv large donation of \$50,000. As some of you may be aware, Gary is separately raising money so that he and two other polio survivors together with carers can go to India and assist Rotary's Now" campaign. Polio Polio Australia is pleased to be in a provide to some position financial support towards this worthwhile venture.

(cont'd P3)

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From the President (cont'd from P2)

And finally, over the last few years, our VP Gillian Thomas has been quietly working away on developing a range of websites containing highly useful information on LEoP for polio survivors and health professionals. The Polio Health site is particularly worth a look. For example, go to www.poliohealth.org.au/polio-australia-videos/ for an excellent series of six short video clips, on topics such as: Best Practice Management of LEoP; Polio Survivors Talk About LEoP; and Future Proofing Polio Services.

John

From the Editor



Mary-ann Liethof Editor

It has definitely turned 'wintery' in Melbourne, after a rather mild autumn. Which is all the more reason I am happy to have a short visit to Queensland scheduled (p4). I don't think I'll be the only 'southerner' up there at this time of year!

There has been much happening and plenty to report on in this edition of *Polio Oz*

News. Perhaps reading through the following pages will be a good way to while away the cold, indoor hours for those of us 'down-under'.

I was a little conflicted to learn about PHI's Executive Director, Joan Headley, retiring (p5/6). Of course, we all have opening and closing chapters in our lives; and whilst I'm pleased for Joan, who can now enjoy more time on her personal pursuits after decades of dedication to PHI, it reminded me that none of us are around forever. All the more reason to celebrate how far we've come in raising awareness on polio's late effects, and also how much more united we've become as a world-wide 'community'.

This is also highlighted in Gillian Thomas's article

on Polio Australia's beginnings (p7). I'm sure those of us who attended the forum in 2007 to discuss forming a national body all believed that, 10 years on, we would have secured the necessary funding to build a thriving service, capable of actively supporting those state networks which are run by passionate, but chronically fatigued, volunteer polio survivors. Alas, the government/philanthropic dollars have not flown our way as yet. However, I believe that this too will change, as certain initiatives being implemented might indicate (p8/9).

And we continue to be supported by many individuals who speak at Rotary and other community meetings, and who organise and/or participate in the annual *Walk With Me* fundraising events (p10). Polio Australia only continues to operate thanks to the dedication of our still active post-polio community members.

Several of these people have already put in their Expressions of Interest to attend the seventh Polio Health & Wellness Retreat on the Sunshine Coast in October (p23). Have you? Whilst there are still a few gaps in the Program, it's almost ready to be uploaded onto the website. Check for updates in the coming weeks.

I hope you enjoy the read!

Mary-ann

How To Exercise If You Are Living With PPS (cont'd from P1)

The principles of safe and effective exercise for people with Post Polio Syndrome are:

- 1. Start gradually up to 30 minutes of
- 2. Moderate level aerobics
- 3. At a moderate pace
- 4. Every second day
- Supervision by a registered physiotherapist or kinesiologist with training and experience about Post Polio Syndrome
- 6. Be careful

Types of exercise for post polio syndrome

I've tried several types of exercise and rate them from most to least effective:

- 1. NuStep
- Walking
- 3. Hand cycle

4. Swimming or water aerobics Good luck with your exercise program and make sure you get a physiotherapist helping you.

The anecdotal comments about physiotherapists are not intended as a criticism. Post Polio Syndrome is not the most common disability and even health professionals may not be fully versed on prognosis, diagnosis and treatment.

For more information, check out Post Polio
International
or the post polio organization in your country.* •

*Browse Polio Australia's Research Papers here: www.poliohealth.org.au/research-categories/

Read Stephen's full and comprehensive article here: http://njnnetwork.com/2017/03/exercise-regularly-if-you-are-living-with-post-polio-

Post-Polio Developments In Sunny Queensland

By Mary-ann Liethof

In June, I am taking a short break from Melbourne's winter in SE Queensland. As Dr John Tierney mentioned in his President's Report (p2), Spinal Life Australia (SLA)—which auspices Queensland's Post-Polio Network—is not only increasing its services to their post-polio members, but also providing both practical and financial support for Polio Australia's work.

There are several initiatives being incorporated into SLA's "2017 strategy to support members with the Late Effects of Polio", which is excellent news for Queensland's post-polio community. Polio Australia is very keen to strengthen relations with SLA, and to provide any assistance we can to help achieve this strategy.

As such, we are delighted to have four members of SLA's allied health team attending the Polio Health & Wellness Retreat on the Sunshine Coast in October (p22): Peter Lysaught (Registered Nurse); Anthony Nakhle (Physio); Gail Pitt (Physio); and Patricia Pacheco (OT). The team will be presenting sessions, as well as providing one-to-one consultations throughout the day.

SLA has also agreed to host a Late Effects of Polio Clinical Practice Workshop for members of their allied health team on Wednesday 7th June, which is the primary reason for my visit to Brisbane. This training will be facilitated by

Catriona Morehouse, Neurophysiotherapist and team member for Mt Wilga Private Rehab Hospital's Post-Polio Clinic in Hornsby, NSW. Catriona ran a few of these Workshops for Polio Australia in Sydney, and has generously made herself available to do this session. (See more on the LEoP Clinical Practice Workshops in our new video, mentioned in the item below.) SLA will be videoing the Workshop to create a webinar, which will be used as a training resource for other health professionals. Hopefully, this will eventually translate to an increase in clinical options for Queensland's polio survivors.

I am also excited about initial talks I've been having with a couple of 'new' health professionals who will be involved with the Retreat. Dr Neala Milburn, a Rehabilitation Physician based on the Sunshine Coast, has kindly agreed to present the Plenary on the *Polio Body*. Neala was a Registrar for Dr Ling Lan, who many Queenslanders will be familiar with.

Neala introduced me to Kelly Gerrard, Regional Rehabilitation Services & Allied Health Manager with Noosa Hospital & Nambour Selangor Hospital. Kelly previously worked with Mt Wilga Private Rehab Hospital, and was there in the early stages of setting up their Post-Polio Clinic. So, I will also be meeting up with Kelly to further explore how this might work for the Sunshine Coast. Watch this space!

Polio Australia's Work Caught On Film

Polio Australia commissioned the following videos in 2016. Each one covers a different aspect of the work being done by Polio Australia to achieve our commitment of standardising quality polio information and service provision across Australia for polio survivors.

To view these videos, click on the following link: www.poliohealth.org.au/polio-australia-videos/



Polio Australia in Profile Video length: 5 mins 7 secs



LEoP Clinical Practice Workshops
Video length: 2 mins 59 secs



Polio Survivors Talk About LEoP Video length: 2 mins 22 secs



Future Proofing Polio Services
Video length: 3 mins 9 secs



Best Practice Management of LEoP Video length: 5 mins 10 secs



Post-Polio Conference Overview
Video length: 1 min 56 secs

PHI's Joan Headley To Retire

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Joan L. Headley has announced her retirement, effective September 1, 2017. She began her work with the organization in 1987 and has been Executive Director of Post-Polio Health International for 28 years.

Joan informed the PHI Board of Directors of her intention "with a sense of accomplishment ... My vision was to go beyond awareness and to provide substantive information that could benefit individuals targeted in our mission, regardless of level of disability, personal philosophy or economic status.

"In addition to polio survivors and users of home mechanical ventilation, a vital part of this effort has been the substantial collaboration with many dedicated healthcare professionals. I have had an opportunity to work with and for extraordinary people."

"Joan L. Headley has been in a real way the heart of PHI for nearly three decades," PHI's Board of Directors said. "She will be greatly missed."

The Board also reaffirmed "our mission of providing accurate and reliable information regarding post-polio syndrome and home mechanical ventilation through Polio Place (polioplace.org and ventnews.org) and through direct contact with our staff."

A search has begun to hire an executive director to replace Joan and to maintain PHI's operations.

Building on the work of advocates Gini Laurie and Judith Fischer, Joan greatly expanded networking among polio survivors, ventilator users and medical professionals across the globe during her tenure.

PHI emerged under her leadership as the acknowledged worldwide hub of information regarding post-polio issues, home ventilator use, and independent living education and advocacy.

Joan coordinated seven of PHI's international conferences. She presented at 70+ meetings, speaking on topics related to post-polio issues, home mechanical ventilation and disability rights. She served on the Post-Polio Task Force (1997) and served on the March of Dimes International Conference executive steering committee (2000).

The networking focus of the international conferences was intentional. Leaders and potential leaders learned, linked up and created new organizations.



Joan says, "I think we should be proud of PHI's years of information dissemination to groups around the world encouraging them to 'do it their way."

Another accomplishment under her leadership was the creation of PHI's Research Fund in 1995. The ability to fund grants elevated PHI a step above the many other information givers. The fund has supported 10 grants since 2001.

She directed the development and growth of communications from PHI and International Ventilator Users Network (IVUN). IVUN was established in 1987 to build upon the polio survivor history of using ventilation at home and to promote its use for other diagnoses.

PHI's publications include Post-Polio Health, Ventilator-Assisted Living, the PHI Membership Memo and an Association Membership Communiqué for post-polio support groups and organizations. Other resources include the Post-Polio Directory, the Resource Directory for Ventilator-Assisted Living and the Home Ventilator Guide. Additionally, PHI and IVUN has taken positive advantage of social media.

Joan, who had polio in 1948 at 15 months, received a degree in biology from Huntington University, Huntington, Indiana, in 1969. In 1974, she received her MS in Education from Indiana University. She taught junior high science and high school biology for 18 years before joining the organization.

-William G. Stothers President of the Board of Directors

PHI's Joan Headley To Retire (cont'd from p6)

Joan is one of those people who many of us thought would be around forever. The PHI Board will certainly have a challenging time filling her role; Joan's extensive experience and knowledge is simply irreplaceable. Over the years, she has built a significant legacy for those of us in 'polio-world'. However, time is forever moving forward, and change is inevitable. I'm sure Joan is leaving everything as organised as possible, although whoever follows will still have to find their own way into the position.

Personally, I don't believe I would have achieved what I have without Joan's guidance and direct assistance. I first contacted her in 2004, when I started with Polio Network Victoria. The PHI website was definitely my 'go to' place for information. And in 2007/08, I couldn't have pulled together my Churchill Fellowship itinerary without Joan's suggestions and intervention on my behalf. Then came the 2009 Post-Polio Retreat and Conference in Warm Springs, Georgia, which really set the scene in my head for what I might be able to do in Australia – especially after I started at Polio Australia. And the rest is history! That's all thanks to Joan.

I sincerely wish Joan all the very best in her retirement, and hope this new chapter brings her contentment and more time to smell the roses! \bigcirc

– Fd

Winning Friends And Influencing People



The first half of the year has included several interesting meetings with people from near and far.

In March, I joined polio survivors and advocates, Frances Henke (far right) and Dr Margaret Cooper (far left), for a meeting with the (then) recently appointed Minister for Health and Minister for Sport, the Hon Greg Hunt MP. Greg has been a long time Parliamentary Patron of Polio Australia, and it was a great opportunity for us to visit his electoral office in Hastings, Victoria, to present him with a *Proposal to Support Polio Survivors*.

Polio Australia's Executive is heading off to Canberra again in June, where we hope to follow up on our Proposal.

In April, I was also presented with the opportunity of spending a day in Geelong with Board Member, Gary Newton, where I spoke to the Post-Polio Support Group, we recorded a radio interview, and gave a joint presentation to the Geelong West Rotary Club.

At the Support Group meeting, I was delighted to meet up with Mick (far right) and Viv (far left) Harper who were visiting from England, Mick is Chairman of the British Polio Fellowship in Lincoln.

It's interesting to know that, wherever you go, it is possible to meet up with fellow polio survivors—a bit like Rotary!



Also in April, Post-Polio Victoria's Liz Telford (far right)

and I met with Dr Kate Armstrong, President of CLAN Child (far left) and Dr Rabia Baloch from the National Institute of Child Health in Karachi, Pakistan.

Kate is based in Sydney, but is working with Rabia to establish a much needed rehabilitation service for polio survivors in Karachi. Rabia was in Melbourne, Australia, to attend and present at the World Congress of Public Health.

The Birth And Role Of Polio Australia

By Gillian Thomas, Vice President, Polio Australia and President, Polio NSW

The individual Australian and New Zealand Post-Polio Networks first met as a group in 1991 at a conference in Victoria. Here representatives of the various Networks present got together to have a chat about common experiences. As a result, "Polio Australasia" was born. There were no formal structures put in place, but at least we were talking to each other and exchanging newsletters.

In 1992 the Networks met again, this time in Adelaide at the "Polio Partnership" Conference. This meeting resolved to develop a constitution and look to formalising the structure so that the Networks would have a true "Australasian" voice.

The NSW Network got the ball rolling early in 1994, circulating to all Networks a sample constitution for comment, undertaking to collate comments and prepare a draft constitution for consideration by all Networks at the New Zealand conference. The draft was completed and circulated a few weeks before the conference which was held from 23 to 25 September 1994.

In New Zealand, Network representatives met on the first day of the conference. Delegates from New South Wales, Victoria, Queensland, South Australia and Western Australia, as well as from New Zealand, were present. After giving informal reports on Network activities since we'd last met, the delegates considered the constitution. After much discussion, it was decided that the Australian and New Zealand networks would be better at that time to remain as a loose grouping of co-operating societies, exchanging newsletters and information and supporting each other's conferences.

We also talked about the location of future conferences. New Zealand said they may hold

another conference in 1998, while Victoria was interested in organising "Polio 2000". New South Wales was asked to consider holding a conference in 1996, which was duly held over three days in November that year. It was called "Living with the Late Effects of Polio".

Victoria in its turn held the "Polio 2000" conference in Melbourne in January 2000. At the conclusion of that conference, Network representatives again met for an informal chat and once more tried to set up a structure whereby we could communicate with each other more readily. The late John Foyster (South Australia) set up an email list, but it regrettably soon fell by the wayside despite the best efforts of some members to keep the impetus going.

By 2005 it had become clear that informal collaboration was not the answer. So following another ad hoc meeting of Network representatives following Polio Network Victoria's Polio Day in October that year, I floated the idea of a "Think Tank" where we could all get together in a more structured setting and really debate the issues that are affecting us and our ability to keep the predominantly volunteer Networks going. I expressed the hope that a National Plan be developed with input from could stakeholders to ensure that polio survivors receive the information, the services, and the support they need into the future.

All Networks enthusiastically took up the challenge and we formally met on 3 and 4 May 2007 in Parramatta, Sydney, to debate these issues and formulate strategies to, as the Conference title stated, "design a future". Who better to do so?

Over the next twelve months, a Memorandum of Understanding was developed and agreed by each State Network, a Constitution developed and adopted, and Polio Australia Incorporated



The Birth And Role Of Polio Australia (cont'd from P7)

became a reality. Separately, we maintain a collaborative and productive working relationship with Polio NZ.

It is important to point out here that the role of Polio Australia is not to replace the Networks, who continue independently as they always have providing information and support to their state members. Polio Australia does not offer individual memberships, rather its members are the State Networks and its focus is on standardising quality polio information and service provision across Australia for polio survivors. Polio Australia's Board comprises two members from each State Network, and up to three independent Directors with specialist skills (two of the latter positions currently being filled).

The task of properly resourcing Polio Australia is a never-ending priority. Trips to Canberra to educate politicians and public servants about the long-neglected needs of polio survivors have become an exhausting but necessary norm. Ageing volunteer polio survivors with increasing disability will not be able to keep going indefinitely, providing services on a shoestring which should rightfully be properly resourced. We are also actively seeking to establish partnerships with and obtain funding from corporate and

philanthropic sources, as well as encouraging polio survivors to think about us in their wills and/or make regular donations where possible to help sustain our work on your behalf.

In 2009 we were fortunate to secure a small amount of philanthropic funding. This enabled us to open our national office in Melbourne in January 2010 and employ Mary-ann as our parttime National Program Manager for two days a week for one year. Mary-ann's hours were increased to full-time in January 2011, following a generous three-year grant from The Balnaves Foundation. Despite having only ad hoc funding since January 2014, with prudent financial management we are still here! With Mary-ann's drive and initiative our achievements since 2010 have included six highly successful polio health and wellness retreats (with the seventh to be run in October this year); this quarterly newsletter, distributed by email to over 2,500 subscribers in Australia and overseas; a series of clinical practice workshops in partnership with Rotary; and, in 2016, our crowning achievement to date, the first Australasian-Pacific Post-Polio Conference – Polio: Life Stage Matters.

We remain ever hopeful that we will be able to obtain sufficient ongoing funding to maintain and expand our staff to enable our full suite of nationally-consistent information and education programs to be rolled out across Australia.

Team Building At Polio Australia

In order for Polio Australia to achieve financial security into the future, it is necessary to engage staff who are dedicated to seeking out and securing funding across a range of sources. This is now possible with funding from Spinal Life Australia.

An experienced **Fundraising Officer** is being sought to work for **20 hours per week**, based at Polio Australia's Head Office in Kew, Victoria. The aim of this position is to research and apply for much needed capital from sources such as: government funding rounds; philanthropic project grants; corporate sponsorship; and Rotary.

An experienced **Administration Officer** is also required for **24 hours per week** and will also be based at Polio Australia's Head Office. The aim of this position is to support all staff members to perform their duties in an effective and timely manner.

Both positions require 'self-starters' who have several years' experience, a range of professional office skills including computer literacy, and wide ranging networking ability. A passion for working with our post-polio community would also be highly regarded!

Employment would most likely commence in July, but this could be negotiable for the right person.

This notice is an early call for Expressions Of Interest. So if you, or anyone your know, would like further details, please send us an email to: office@polioaustralia.org.au and provide a few details of your background, and why you'd like to join the Polio Australia 'team'.



Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 January to 30 April 2017. Without which, we could not pay our rent, outgoing expenses, or staff!

Hall of Fame

Name	Donation
Jill Pickering	\$8,000.00
Sue Mackenzie	\$2,900.00
	Total-\$10,900.00

General Donations

Names						
Jill Burn	David Miller	Liz Telford	Gillian Thomas			
Post-Polio Network We	estern Australia	a Margue	rite Swann Anonymous			
Total—\$2,283.90						

Rotary Donations

Club	Donation			
Rotary Club of Bribie Island	\$115.00			
	Total—\$115.00			
Grand Total-\$13,298.90				

Introducing Samantha (Sam) O'Meara



In June 2017, Sam O'Meara ioins Polio Australia in the new role of Community Engagement and Bequest Officer. She brings a strong set of skills to the role, including ongoing volunteer telephone work crisis support with Lifeline at the Bendigo and Ballarat offices in Victoria. Sam is about to complete a

Master of Social Work at Latrobe University in Bendigo, but has also achieved a Graduate Diploma of Psychology, and a Bachelor of Psychological Science and Minor of Philosophy.

Sam's role includes contacting members of our post-polio community who have had previous involvement in Polio Australia's activities such as our annual Health and Wellness Retreats, various lobbying campaigns, and *Walk With Me* events, primarily to have a friendly chat about how

you're travelling, and to provide an update on Polio Australia's current and upcoming programs and activities.

Sam is also tasked with implementing Polio Australia's fledgling Bequest program, and assisting supporters interested in including a gift to Polio Australia in their Will.

If you would like to contact Sam, her details are: Ph: 0466 719 613

Email: sam@polioaustralia.org.au

More information about Polio Australia's Bequest program can be viewed here:

www.poliohealth.org.au/bequest-program-video

Three out of four Australians support charities throughout their lifetime, but only 7% of Australians include gifts to their favourite charities in their Will.

Walk With Me Brisbane

Board Member, Sue Mackenzie (pictured below with husband, Graeme, and friend), continues to raise awareness and funds in Brisbane, through Rotary Meetings and Conference presentations.

Click the following link to view Sue's speech (photo below right) at the Rotary Club of Burleigh Heads Black Tie "End Polio Now" Charity Dinner in March: www.facebook.com/PolioAustralia/

Sue also is also planning another *Walk With Me* activity to be held in September. (See below for more details.)





Walk With Me

Please help me make a difference and fundraise for Polio Australia through our Brisbane Challenge!

WHEN: Saturday 16th September

9.30am for 10am start

START: New Farm Park Area (Brisbane, Qld)

ROUTE: TBC

DISTANCE: 1.5 kilometres (750 metres each way)

relaxed walk or wheel ride.

REFRESHMENTS: TBC

REGISTRATION: \$20 online or on the day.

DONATE: The 2017 Walk With Me webpage with information for September (and

for November in Canberra) will be 'live' as from the 1st of July for

Donations and Registration.

Visit the website now: www.polioaustralia.org.au/walk-with-me/, where

you can also view the Walk With Me activity video.

All donations are tax deductible and a Polio Australia receipt will be emailed.



Chronic Pain and PPS Research Project



A big thank you to all Polio Oz News readers hank You Polio Oz News readers who have kindly given us their time, and who have gone the extra mile to

share this research study with friends. We have also received emails from members sharing their experiences with polio, post-polio syndrome and pain, and sharing the variety of strategies they use to manage the pain and to keep themselves physical and mentally active.

We have had over 80 people complete the survey so far. We have had a great response from a wide variety of people - ages range from 32 to 88 years! 70% respondents have been female, and a massive 80% have chronic pain related to their PPS. This is a major health problem, and we are hoping that this research will help to focus attention on the condition.

We hope to get 150 respondents, so if you haven't had a chance to complete the survey, we would be most grateful if you could do it **before** the study finishes on 1st of July 2017.

Who?

University of Technology Sydney (UTS) Master of Clinical Psychology student, Kristine Koh, and supervisor Dr Toby Newton-John, are conducting a research project and would like to invite members with Post-Polio Syndrome (PPS) who are experiencing chronic pain to take part.

They are hoping to recruit between 100 and 200 participants.

What?

research is investigating the experiences of people with PPS and seeks to identify the different coping strategies used to manage chronic pain in daily life. It is also hoped that this research can shed light on how the use of different coping strategies affects the experience of chronic pain and PPS. It is an important area that has not been adequately investigated, and this research project will extend the scientific study of PPS. We hope to use the information in order to significantly improve quality of life for people with PPS and chronic pain.

How?

This study involves completing a survey online at your convenience. The survey will take 25 to 35 minutes your time, but you have to complete it over one week. To begin the survey, click on or enter the link below into your web browser: http://tinyurl.com/ChronicPain-PostPolioSyndrome

If you have any questions, please email either: Kristine: weilingkristine.koh@student.uts.edu.au

or

Dr Toby Newton-John: toby.newtonjohn@uts.edu.au

Virtual Reality 'Mindfulness' Trial To Relieve Pain

Christopher (Chris) Tia is a self-confessed 'technerd' and a polio survivor. He is partnering with Spinal Life Australia and Griffith University to develop this trial for polio survivors. For more details, check Chris's fundraising page here: https://startsomegood.com/virtualmindfulness

Project

Helping the physically disabled manage pain and associated stress through 'Virtual' Mindfulness

What is the project and how will it create positive change?

The project will trial the use of Virtual Reality technology to deliver a course mindfulness techniques to relieve pain and associated stress for the physically disabled. VR technology has been chosen as a medium to potential physical barriers participants while allowing them to 'virtually' attend.

Why Mindfulness?

There are many peer-reviewed scientific papers to prove the effectiveness of mindfulness in reducing pain and enhancing the mental and physical well-being of people.

Many hospitals and medical professionals now prescribe mindfulness techniques to help patients cope with suffering – from illnesses such as cancer and arthritis, to longer term conditions such as chronic fatigue syndrome.

Clinical trials suggest mindfulness can help reduce the average pain 'unpleasantness' levels by 57% to 93%. It has also been demonstrated to improve the quality of life for those in chronic pain conditions - from fibromyalgia to cancer.

What will success look like and how will outcomes be measured?

Feedback from participants will be gathered at the start and conclusion of the trial. Initial feedback will be used as a baseline of each participant's state in relation to pain and quality of life. The final feedback will be used to measure the impact of change in each participant's involvement in the trial. It is anticipated 5-10 participants will be required.

Where is the project located?

While the project's resources will be concentrated in Sydney, project participants and stakeholders may be in either Sydney, Brisbane or Melbourne. This will not be an issue as many of the tasks and communications can be conducted remotely.

International Launch Of Luggie Powerchair (advertisement)

radical high tech portable Luggie powerchair from Taiwanese company Freerider Corp was launched at the Sydney ATSA Expo on May 10th by Freerider's International Sales Director, Jason Huang.

"We've been working with Scooters Australia for over 6 years now and the ATSA Expo happened to come along at the right time for us to launch this great new powerchair onto the world market," said Mr Huang.

While the Luggie scooter is already the biggest selling folding mobility scooter in the USA and Europe this new addition to the range further cements Freerider as the class leader in powered portable mobility products.

The new powerchair takes some of the same scooter technology and applies it to an electric wheelchair to produce a stylish and highly portable chair that makes travelling so much easier for those that have trouble walking distances.

The Luggie range has been designed by a German / Taiwanese collaboration that focuses on producing a range of mobility products that can be easily folded and stored, whether in the hold of a plane, the boot of a car or caravan, or even in the cabin of a cruise liner.

With lightweight Li-ion batteries that are IATA approved, travelling internationally with a Luggie makes touring that much easier for many people.

Managing Director of Scooters Australia, Peter Fraser, says that the travel the market is experiencing strong growth potential around the developed world.

"With the advent of the baby boomers into this market, there are many people whose lifestyle expectations haven't changed since they were younger, even if walking long distances is not so easy any more," says Mr Fraser.

"And travel is one of the main drivers for

those who have retired that easier if the going gets a

from work but not from life, and a Luggie just make it much

bit tough. It's a real game changer," he says.

"Luggie scooters and powerchairs make sense in this newly emerging market and we expect further growth as this demographic increasingly moves into retirement," says Mr Fraser.

scooters

More information at: www.scootersaus.com.au







1300 622 633 www.scootersAus.com.au

Shoulder Problems In Polio Survivors

By Dr William DeMayo, MD

Source: DeMayo's Q & A Clinic—February 2017

DeMayo's Q & A Clinic is a monthly forum which has been established by the Pennsylvania Polio Survivor Network. Visit their website to read more excellent articles here:

www.papolionetwork.org/demayos-q--a-clinic.html

Question: I am now 86 and contracted polio when I was three. The polio left me with paralysis in my left arm, the muscles of my stomach and I have a slight curvature of the spine. Over the years I have been doing fine and even bore 5 children.

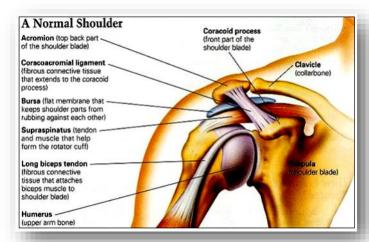
About two years ago I developed horrible pain in the upper part of my right arm. I am allergic to NSAIDs so I use Tylenol which gives me occasional partial relief. I also use creams such as Blue Emu and have had therapy. Also, occasionally I use Icy hot electrodes. The pain is with me daily however it does not interfere with my sleep. I am able to be fully responsible in my daily requirements but with pain. I am truly blessed that I am not dealing with worse.

I was curious if you may have any recommendation so that I can make the pain leave. I have also been told I have arthritis in the area.

Reply: Shoulder problems in the elderly can be very difficult to rehabilitate and this is especially true in the polio population. A comprehensive review of shoulder problems is well beyond the scope of this article, but I will share some perspectives that may be helpful.

First, it is important to remember that the shoulder joint is inherently unstable without muscular support. Polio survivors with weakness of shoulder muscles can learn to substitute but are clearly at much higher risk for subsequent problems such as arthritis, shoulder impingement, bursitis, and tendinitis because the shoulder simply cannot function as it was originally designed.

In order to understand this fully, a basic knowledge of shoulder anatomy is essential (see above). One only has to glance at the shallow "cup" (socket) of the shoulder blade which articulates with the humeral head in order to appreciate the importance that soft tissues play in stabilizing the joint during normal use. normal use. Without normal muscle strength, the ball simply does not move normally within the socket. When the ball does not move normally within the socket, other muscles are overused, leading to possible muscle and tendon problems. Many polio survivors with leg weakness rely on their arms and shoulders to get up from a sitting



position, to bear weight on crutches/walkers, or to push a wheelchair. The shoulder is simply not designed for this kind of regular weight bearing function. Given the history and location of your pain, arthritis of the humeral head and "cup" (a.k.a. glenoid fossa) is a likely component of the problem you described.

Other possible contributing sources of pain, however, should always be evaluated. Although not likely in this case, polio survivors should always be aware of other diagnoses to consider when you have a complaint of shoulder pain.

- A pinched nerve of the cervical spine (neck) can radiate pain to the shoulder.
- Myofascial pain (chronic muscular pain) can develop in the periscapular muscles around the shoulder.
- If falls have occurred then traumatic injuries such as a humerus fracture or shoulder separation (torn or partially torn ligaments between bones in the shoulder) should be considered.

Additionally, there are multiple chronic inflammatory problems that occur frequently in the shoulders of polio survivors. These can lead to abnormal shoulder biomechanics (abnormal movement within the shoulder) that over time can contribute to arthritis. It can be important to treat these inflammatory problems early rather than simply endure the pain because problems can snowball as one gets older. Some of these inflammatory problems include:

- Bicipital Tendinitis (inflammation of the biceps).
- Bursitis (inflammation of the fluid-filled sac).
- Rotator Cuff Tendinitis (inflammation of the tendon portion of the rotator cuff muscles that stabilize the shoulder joint).

Read the full and comprehensive article here: www.papolionetwork.org/uploads/9/9/7/0/99704804/shoulder-problems in polio survivors.pdf

Post-Polio Health International Online Resources

Two Sections added to Polio Place! www.polioplace.org

Check out <u>PHI-Funded Research</u> and <u>Articles from Post-Polio Health</u>. The section includes major articles from the quarterly newsletter of Post-Polio Health International. Prior to 2003, it was called *Polio Network News*. The articles are organized by topic.



Breathing problems? Check out IVUN. www.ventusers.org



Treatment With L-citrulline In Patients With PPS

Study protocol for a single-center, randomised, placebo-controlled, double-blind trial

Authors:

- Simone Schmidt[†]
- Vanya Gocheva[†]
- Thomas Zumbrunn,
- Daniela Rubino-Nacht,
- · Ulrike Bonati,
- · Dirk Fischer, and
- Patricia Hafner

Source: BioMed Central - 9 March 2017



Abstract

Background

Post-polio syndrome (PPS) is a condition that affects polio survivors years after recovery from an initial acute infection by the Poliomyelitis virus. Most often, patients who suffered from polio start to experience gradual new weakening in muscles, a gradual decrease in the size of muscles (muscle atrophy) and fatigue, years after the acute illness. L-citrulline is known to change muscular metabolism synthesis by raising nitric oxide (NO) levels and increasing protein synthesis. This investigator-initiated, randomised, placebo-controlled, double-blind, trial aims to demonstrate that L-citrulline positively influences muscle function and increases muscular energy production in patients with PPS.

Methods/design

Thirty ambulant PPS patients will be recruited in Switzerland. Patients will be randomly allocated to one of the two arms of the study (placebo:verum 1:1). After a 24-week run-in phase to observe natural disease history and progression, participants will be treated either with L-citrulline or placebo for 24 weeks. The primary endpoint is change in the 6-min Walking Distance Test. Secondary endpoints will include motor function measure, quantitative muscle force, quantitative muscle magnetic resonance imaging and magnetic resonance spectroscopy and serum biomarker laboratory analysis.

Discussion

The aim of this phase IIa trial is to determine if treatment with L-citrulline shows a positive effect on clinical function and paraclinical biomarkers in PPS. If treatment with L-citrulline shows positive effects, this might represent a cost-efficient symptomatic therapy for PPS patients.

Trial status

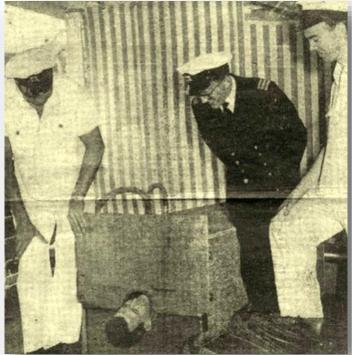
The trial started enrolment in June 2016 and is expected to be completed by the end of August 2017.

Barrow Carpenter Made Iron Lung At Sea

Source: North-West Evening Mail

- 17 April 2017

BARROW ship's carpenter Gordon Burrow had to turn his hand to all manner of tasks at sea – but none so odd as a the request to build an iron lung for a woman who fell seriously ill with suspected polio.



Working well: An Orion crew member tries the iron lung for size watched by, from left, plumber A. Newcombe, ship's surgeon Dr D. M. Stainton-Ellis and carpenter Gordon Burrow

Mr Burrow, now 81, and living at Northfleet in Kent, kept news cuttings from his moment of fame almost 60 years ago while serving on the Barrow-built liner Orion.

Poliomyelitis can cause rapid muscle weakness and before the development of a polio vaccine the usual approach was to use an iron lung to maintain breathing.

These steel and glass pressure vessels were not carried on liners – but they were provided with the plans to make one from wood and whatever was available.

Mr Burrow, originally from Ancaster Street, Barrow, said: "We were sailing from London to Sydney and there was a lady who went down with polio. The skipper said: 'I need an iron lung'. I said: 'Tell me what you want and I will make it'."

A search was made of the ship for suitable parts, mostly plywood.

Mr Burrow said: "I made the majority of it and the ship's plumber made the pipework. She was

in a bad way and had trouble breathing."

Fortunately, the woman's condition did not deteriorate as quickly as expected and she did not need to be placed in the completed iron lung.

An article dated May 21 in 1959 noted: "The liner Orion arrived in Sydney yesterday carrying an improvised iron lung built on board to save the life of a woman passenger. The passenger had become ill soon after leaving Colombo on the voyage from London. The ship's surgeon, Dr S. Stainton-Ellis said he had diagnosed the woman's complaint as suspected polio. Her chest muscles were affected and there was a danger she would suffocate. Dr Stainton-Ellis said he had decided to build an improvised iron lung to keep the woman breathing until she reached Fremantle. Ship's carpenter G. Burrow, of Barrow, and ship's plumber A Newcombe, of London, had worked non-stop for 36 hours to build it. The lung was made of plywood, engineroom piping, two pairs of bellows and rubber for sealing portholes.

The woman was said to be aged about 30 and had been travelling to Melbourne with her husband and two children.

Another news cutting kept by Mr Burrow from 1959 noted: "The lung is still aboard the Orion as an example of the ingenuity of the liner's crew. Plans for an emergency iron lung, drawn from one made on the liner Ruahine some years ago, are carried on all Orient liners. Dr Stainto-Ellis said that the lung, six feet long and two feet by two feet, had been tested by one of the crew and worked satisfactorily."

Postscript: We wonder where this lady might be today? If still with us, she would now be 89 years old.

-Ed



Eradicating Polio

Polio: Health organisations call for final push to eradicate highly contagious disease

By Julie Power

Source: Sydney Morning Herald – 30 April 2017

Christopher Tia [pictured right] was three when he was paralysed by polio for months. His two older brothers were vaccinated, but not him.

"They ran out of the [polio] vaccine", said Mr Tia who now uses crutches to walk. "Unfortunately I drew the short straw, and I have two brothers who are okay", said Mr Tia, who now works in ecommerce. In his late 30s, he contracted polio in Laos before his family emigrated to Australia.

In Mr Tia's lifetime, the number of reported cases of poliomyelitis – which causes irreversible paralysis in one in 200 cases – has dropped from 350,000 in 125 countries in 1998. Last year there were 37 cases. This year, there have only been five cases concentrated in small areas within the only three countries where it is endemic: Afghanistan, Nigeria and Pakistan.

Health organisations are now calling for one final push to eradicate the highly contagious disease that usually affects young children under five.

"It's the closest we've ever got [to eradicating polio]", said Reza Hossaini, the director of polio eradication from Unicef's NY headquarters. "If we don't contain the virus, within 10 years it could go back to 200,000 cases a year", he said.

Unlike measles, the likelihood of getting polio as an adult is less, but adults can still be carriers and circulate the virus. Australia was declared polio-free in 2000.

Mr Hossainiwas part of a delegation visiting Australia this week to call on the Turnbull government to increase funds to the World Health Organisation's global polio eradication initiative. The leader of the delegation, Michael Sheldrick of Global Citizen, said current measles outbreaks – 23 cases in NSW, and several in Victoria, plus the worst outbreaks in years in Italy and the United States – underscored the importance of maintaining high vaccination rates domestically and internationally.

"We are in a race against time. There are still thousands of children who have never been reached, and all it takes is one case in an area with many children, and it can spread like wildfire", he said.

"So long as polio remains anywhere, it is a threat everywhere and Australians should continue to immunise against polio and other diseases, even those that are rare to Australia", Mr Sheldrick said.



Photo: Peter Rae

The impact of polio, even mild cases, lasts a lifetime. Many of the 400,000 Australians who got polio before vaccines were introduced in the 1950s are now suffering from "post-polio syndrome", says Polio NSW. It says there also many young Australians like Mr Tia who got the disease overseas.

The GPEI – a private public partnership including Unicef, Rotary and the Gates Foundation – is lobbying the government to restore funding to previous levels of \$15 million a year from the \$3 million this financial year and a further \$3 million next. But Foreign Affairs and Trade argues it is around \$8 million a year, and complemented by nearly \$300 million in funding over five years to 2020 for other vaccination programs in South East Asia and the Pacific and globally, including Gavi, the vaccine alliance.

"The dual investment approach allows Australia to contribute to global efforts while also protecting our region from the risk of polio reemerging", said a spokesman for DFAT.

Mr Tia urged the government to prevent other children from suffering. "To falter when we are almost at the point of being able to remove such a possibility altogether would be such a shame", he said. "I think in developing countries where the virus is typically prevalent, a disability like polio can have a much greater impact on a person's (and their family's) life than what we could ever imagine in Australia."

Rotary Australia is also disappointed in the funding cuts to the GPEI, which it initiated nearly 30 years ago. Sir Clem Renouf, a Queenslander and the first Australian to become Rotary's international president, convinced WHO to attempt to eradicate polio after Rotary immunised six million children in the Philippines.

"Everyone said it wasn't achievable", said Ken Hutt, the chair of the Canberra region district. Rotarians around the world have raised more than \$1 billion to eradicate polio, and Mr Hutt said they were determined to make polio the second disease (small pox was the first to be eradicated by vaccines) to be wiped out.

Eradicating Polio (cont'd from p15)

To raise funds and spread awareness, Mr Hutt travels NSW talking about polio.

Roy Bennetts, 91, of Kiama contracted polio as a boy in 1930 – 25 years before a vaccine was introduced. The Kiama man missed nearly four months of school and was hospitalised for a month, but says he got off lightly compared to others.

Now he is suffering from post polio syndrome, something few understand, he said. "I have to be careful, my legs collapse, down I go, and bang ... It is causing my hands to close in, I have had them opened up twice, my toes curl up, and my fingers. I have a job walking anywhere", he said.

Mr Tia also worries about his symptoms worsening. Like Mr Bennetts, Mr Tia considers himself lucky – he goes bush walking on crutches in Ku-ring-gai national park, but worries he won't be able to in future.

Gillian Thomas, the president of Polio NSW, contracted paralytic polio as a baby of 10 months old. She is urging the Australian government to honour its financial commitment. "Eradication won't be the end of the story. Polio survivors both here and abroad are the 'forgotten generations' who are now experiencing the late effects of polio – every last adult must be supported", she said.

Obituary: Julius Youngner

Obituary: Julius Youngner | Last surviving member of Salk vaccine team 24 October 1920 — 27 April 2017

By Mark Roth

Source: Pittsburgh Post-Gazette

- 29 April 2017



Dr. Julius Youngner, right, with Dr. Jonas Salk in an undated photo. Credit University of Pittsburgh

As the last surviving member of the team that developed the Salk polio vaccine in the 1950s, Julius Youngner was justifiably proud of his contribution to that landmark effort.

"Dr. Youngner made monumental contributions to the field of virology," Vincent Racaniello, Higgins Professor of Microbiology and Immunology at Columbia University, said in a statement. "For most, simply working with Jonas Salk on the development of the polio vaccine would be enough for a career; he also made important contributions to our understanding of the antiviral roles of interferon, cell culture and

other vaccines."

But Mr. Youngner, who died Thursday [27 April 2017] at the age of 96, never forgave Jonas Salk for his failure to acknowledge Mr. Youngner and the other members of the research team that created the vaccine against the crippling disease.

In a revealing oral history done by the local chapter of the National Council of Jewish Women in 1992-93, Mr. Youngner described what happened. Dr. Salk's announcement of the success of the polio vaccine in field trials in 1955 created a sensation, he said, and the group that had funded the effort, then known as the National Foundation for Infantile Paralysis, knew that "it was much easier to continue raising money when you have a hero, and they had an enormous public relations department that took up Jonas' name as the hero, which he deserved.

"But in the meantime, Jonas was, how shall I say, not very generous to his colleagues and he made sure that nobody else was ever mentioned."

To add insult to injury, Dr. Salk's wife later called Mrs. Youngner and said, "You know, we're really disappointed in your husband, because he hasn't called Jonas and congratulated him." Mrs. Youngner responded with a brusque reply, and the two couples, who had once been close, never socialized again.

Years later, Dr. Salk's son, Peter, made efforts to recognize Mr. Youngner's contribution — as well as the contribution of many others — to the creation of the polio vaccine. ●

Read full article here: http://www.post-gazette.com/news/obituaries/2017/04/28/Julius-youngner-Salk-vaccine/stories/stories

NDIS Update



The 2016 Federal Budget was announced on Tuesday 3 May.
What does this mean for the NDIS?

Source: Every Australian Counts — 6 May 2016

What's the headline?

The Turnbull Government is committed to fully funding the National Disability Insurance Scheme. To meet future costs of the NDIS the Government is establishing an NDIS Savings Fund. The 2016-17 Budget puts \$2.1 billion in this fund.

So, is that enough?

It's a first step, but it's not the full funding needed. The Government's own calculations show that an extra \$4.4 billion must be found in 2019-20 and more than \$5 billion each year after that.

Does that mean the NDIS will be held up?

No. The funds needed to begin the full roll out from 1 July this year are there. It will absolutely go ahead in just a few weeks time. The funds still to be committed are for when the NDIS is there for everyone.

An independent evaluation team led by the National Institute of Labour Studies (NILS) at Flinders University has been set up to explore how the NDIS is making a difference to older people with disability.

The project will compare the supports received by older people with disability who have joined the NDIS with similar people who have not joined. As part of this work, the research team would like to speak with older people with disability aged 64 – 70 years who are not in the NDIS and are living in **South Australia or Victoria**.

This study has been under way for a few months already, but the research team is still looking for more people to interview about their personal experiences. For more information or to register your interest, call 1800 265 648 or send an email to ndisevaluation@flinders.edu.au

Is there anything else in the Budget specific to people with disability?

A few things. The Government has provided \$46.5 million in transition funding for the Mobility Allowance. There's also \$96 million for a Try and Test Fund which the Government says will test policies aimed at reducing long term welfare dependency. And \$118 million has been allocated for school students with disability. We don't have all the details on these items, more news to come.

What are people saying?

The disability community is very happy to hear of the Government's commitment to the NDIS. But some of the welfare reform is causing some concern.

National Disability Services CE Ken Baker said: "NDS sees promise in the \$96 million allocated to the 'Try, Test and Learn fund' to test ways to reduce long term welfare dependency. We hope that this provides the non-government sector with opportunities to attract funding for innovative proposals that build the capacity and independence of people over time."

AFDO CEO Matthew Wright said: "Let's be clear, cutting people off the Disability Support Pension does not create one single job, it just creates poverty. People with disability want to work, but that will only happen if the Government has a jobs plan, not a welfare plan."

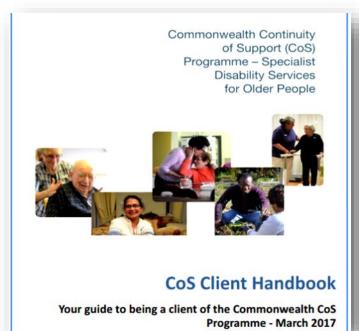
Carers Australia CEO Ara Cresswell said: "Welfare cuts should not be used to fund the NDIS. Carers don't receive direct services under the NDIS, and savings from changes to the Carer Allowance could be better directed to the Government's Integrated Plan for Carer Support Services, which will provide specific carer support."

Physical Disability Australia (PDA) is a national peak membership based organisation for people with physical disability, and it's on the hunt for more members. If you have a physical disability or know someone who does then please consider becoming a member of PDA. Having more members will help PDA speak with authority when it raises issues that impact on the lives of people with physical disability. PDA is actively working to ensure the needs of all Australians with Physical Disability are taken into account by the National Disability Insurance Agency (NDIA) and other Federal, State and Territorial government departments.

To find out more about PDA, check-out their website: www.pda.org.au

Membership in PDA is free and open to all Australians with physical disability, their family members and supporters.

Commonwealth Continuity Of Support Handbook



Introduction

This handbook aims to help you understand the Commonwealth Continuity of Support (CoS) Programme. It has four sections:

- Accessing CoS This is about who is eligible, when it starts and what you need to do.
- **Being a CoS client** This covers services you can and cannot access under CoS.
- Changing needs and leaving CoS This is about reviewing your supports and getting the services you need.
- **Support and more information** This covers the types of support such as advocacy programs and other resources and information that can help you.

This handbook is based on the Commonwealth CoS Programme Manual developed for service providers. The manual received input from state and territory governments and a wide range of disability and aged care peak bodies including consumer advocacy organisations. This handbook also received comment from individuals and aged and disability peak organisations.

Summary

The CoS Programme aims to help older people with disability receiving state-managed specialist disability services who are not eligible for the National Disability Insurance Scheme (NDIS).

If this is you, CoS will offer the same support services you were getting before you moved to this program.

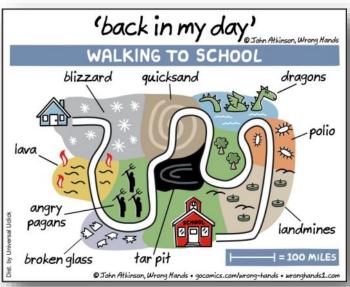
When your care under CoS begins, the Department of Health will manage your services instead of your state or territory government.

What you need to know:

- You will continue to receive your existing services until you move to CoS.
- You do not need to be assessed again to enter CoS.
- You can stay with the same service provider. If the service provider cannot do this, we will help you find a new service provider.
- You will receive the same supports you were receiving at the time you move to CoS.
- If you pay a fee for services now, this amount will not change under CoS. If you don't pay fees, this will not change.
- If this is how you received your supports before, you can remain on an individual budget model under CoS.
- Once you begin as a client under CoS, if your needs change your service provider will undertake (or organise) a review of your supports.
- Depending on the outcome of this review, there are some options where you can stay in CoS and get the extra supports you need.
- However, as was the case when you were receiving state-managed specialist disability services, for other clients whose needs change they will leave CoS and enter aged care services.
- Aged care may offer many clients the services that best match their needs. Support is available if you need to leave CoS and access aged care supports.

Download the PDF version here:

https://agedcare.health.gov.au/sites/g/files/ net1426/f/ documents/04 2017/31 march 2017 final client handbook.pdf



Cartoon in Time p.18, March 27, 2017

SMS Technologies To Enhance Polio Surveillance

Using SMS technologies to enhance polio surveillance

Source: WHO Sierra Leone

A new SMS-based reporting system has been introduced in Sierra Leone to improve identification, detection and reporting of suspected acute flaccid paralysis (AFP) cases in children less than 15 years, with the initial training of 520 health workers and community informants.

AFP surveillance is part of the global polio eradication strategy which requires health workers to promptly report and investigate any sudden onset of paralysis in the limbs of children or adults in order to confirm or rule out the circulation of wild polio virus, and is essential for polio-free certification.

The SMS reporting system known as Auto-Visual AFP Detection and Reporting (AVADAR) aims to facilitate:

- Instant notification of an AFP case with a minimum set of information collected at the community level.
- Weekly reporting by health workers and community informants to a central server, on the presence or absence of AFP cases in their respective communities.

The training participants will form an effective surveillance network for the reporting of any acute or sudden onset of weakness or floppiness of one or more limbs in a child under 15 years of age, or any person of any age with paralytic illness in whom a clinician suspects polio.

Training beneficiaries have to date included national and district level officials from the Ministry of Health and Sanitation, WHO surveillance staff and CDC -STOP teams, community health



technology into use to report suspected AFP cases in her locality WHO/S Gborie

workers and community informants. This latter group includes traditional and spiritual healers, influential youths and traditional leaders, among others.

At the end of the training the informants were given GPS-enabled phones and solar chargers to carry out active case searches using their phones to report cases seen in their communities for further investigation. District and national health authorities will then automatically receive notification alerts in their AVADAR phone from all the informants, whenever a suspected AFP case is detected and reported.

The AVADAR project will be implemented by the Ministry of Health and Sanitation in four pilot districts including Western Area Urban, Western Area Rural, Kono, and Tonkolili with the support of a consortium of development partners including WHO, Novel-T, eHealth Africa; UNICEF, CDC and the Bill and Melinda Gates Foundation.

Israeli Scientists Find Way To Detect Polio Earlier

By Times of Israel Staff

Source: Times Of Israel - 3 April 2017

Israeli scientists have developed an improved model for detecting the poliovirus before it spreads and causes an outbreak, Ben-Gurion University of the Negev said Monday.

Researchers from the Beersheba University described in a paper published last Wednesday in "Science Translational Medicine" their new methodology, which uses levels of the virus in sewage waste to predict an outbreak instead of waiting for reports of paralyses among people.

The virus has been eradicated from most countries in the world, following a three-decade effort to eradicate the crippling disease. However, a major obstacle is the reintroduction of a wild poliovirus from an endemic country to a previously polio-free country.

Using data from an outbreak of wild polio in Israel in 2013, the team, led by Yakir Berchenko, developed a model that uses environmental surveillance to get a more sensitive result than the alternative of waiting for the disease to strike.

In late August 2013, a wild poliovirus was identified in sewage samples taken in the southern Galilee. According to the Health Ministry, the sample was taken before the launch that month of a nationwide vaccination effort against the virus.

Achieving A Polio-Free World

By Anne Schuchat, MD (RADM, USPHS), Contributor

Acting Director, Centers for Disease Control and Prevention (CDC); Acting Administrator, Agency for Toxic Substances and Disease Registry (ATSDR)

Source: <u>Huffington Post</u>—28 April 2017

When I first joined CDC as a disease detective in 1988, polio was far from extinct. Nearly 1,000 children were paralyzed each day by the disease, mainly in poor and developing countries. And although polio had already been eradicated in the U.S., many Americans still remembered the fear associated with polio outbreaks and the era of iron lungs and leg braces. My father didn't learn to swim because of concerns about the spread of polio in public swimming pools.

The same year I came to CDC, the World Health Assembly announced a commitment to eradicate polio – and the crippling and potentially fatal infectious disease is now on the brink of extinction. Only five cases have been reported worldwide so far this year – three in Afghanistan and two in Pakistan. The reason for this remarkable accomplishment: widespread polio vaccination.

With <u>World Immunization Week</u> currently under way, the on-the-ground gains of recent years are striking. An estimated 2.5 billion children have been vaccinated against polio since 1988. This progress was made possible through <u>Global Polio Eradication Initiative</u> partners including Rotary International, CDC, World Health Organization, UNICEF, and the Bill & Melinda Gates Foundation, and through the efforts of tens of thousands of health workers across the globe – some of whom have risked their own safety to distribute lifesaving vaccines in conflict zones. We are now closer than ever to achieving a polio-free world.

Polio virus continues to circulate in three countries: Afghanistan, Pakistan and Nigeria. Unfortunately, vaccinating children in these security-compromised areas can be a difficult and dangerous task. In Nigeria, for example, more than 360,000 vaccinators support a national polio campaign, and another 180,000 are engaged for sub-national campaigns. More than 80 percent of vaccinators work in the northern part of Nigeria, where they go house-to including high-risk in areas, administer vaccine to children. As a result, 4.7 million children received vaccine through special interventions in eight northern states in 2016. Female polio workers play a unique role in these efforts. In some regions, mothers and female caregivers will open doors only to women workers who are accepted where men cannot go. Without physical access to administer multiple

doses of vaccine, it is not possible to reach these children and stop polio.

Despite the obstacles, these countries are making substantial progress, largely due to the tireless efforts of these brave women and men. But as long as pockets of unvaccinated children exist, polio remains a threat to children everywhere.

Physicians practicing in the U.S. today might never have seen a patient with polio. And around the world, the memory of the disease is becoming cloudy. Today, 16 million people who statistically would have been paralyzed by polio, are walking because of the polio eradication initiative. But until polio is gone everywhere in the world, the risk of new outbreaks persists.

To accomplish this goal, we must continue working together to improve immunization delivery and vaccinate those children in hard-to-reach, insecure areas. A vast global laboratory and surveillance network and a well-trained public health workforce ready to respond to disease outbreaks is essential to this mission. We also depend on scientific and technical expertise that not only supports polio eradication, but has been essential to critical public health responses against measles, Ebola and other infectious diseases.

It has been more than 35 years since the world eradicated smallpox, the first disease ever eradicated from humans. When we succeed in reaching and vaccinating almost every child against polio, we will eradicate it for good – and guarantee future generations a world that is forever free from polio.



CDC A female health worker administers the polio vaccine to children in Nigeria.

Polio This Week

Source: Polio Global Eradication Initiative — as of Wednesday 31 May 2017

Summary of newly-reported viruses last week: Afghanistan, one new wild poliovirus type 1 (WPV1) environmental sample. Pakistan, seven new WPV1 environmental samples. Democratic Republic of the Congo, four new cases of circulating vaccine derived poliovirus type 2 (cVDPV2) and one isolate from a healthy individual in the community. For more, see relevant country sections.

Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

Total cases	Year-to-date 2017		Year-to-date 2016			Total in 2016	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	
Globally	5	4	16	3	37	5	
—In Endemic Countries	5	0	16	0	37	2	
—In Non-Endemic Countries	0	4	0	3	0	3	

Case breakdown by country

Countries	Year-to-date 2017		Year-to-date 2016		Total in 2016		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	3	0	5	0	13	0	21-Feb- 2017	NA
Democratic Republic Of The Congo	0	4	0	0	0	0	NA	18-Apr- 2017
Lao People's Demo- cratic Republic	0	0	0	3	0	3	NA	11-Jan- 2016
Nigeria	0	0	0	0	4	1	21-Aug- 2016	28-Oct- 2016
Pakistan	2	0	11	0	20	1	13-Feb- 2017	17-Dec- 2016

NA: onset of paralysis in most recent case is prior to 2015. Figures exclude non-AFP sources. Lao PDR cVDPV1, all others cVDPV2. cVDPV definition: see document "Reporting and classification of vaccine-derived polioviruses" at [pdf]



http://polioeradication.org/polio-today/polio-now/this-week/







Polio Health and Wellness Retreat Body / Mind / Spirit

SurfAir at Marcoola, Queensland Thursday 26, Friday 27, Saturday 28 and Sunday 29 October 2017

Expression of Interest Only

Polio Australia will once again be facilitating its 3 day Polio Health and Wellness Retreat for polio survivors and their partners/family members from Thursday 26 to Sunday 29 October, 2017 on the beautiful Sunshine Coast in Queensland. The holistic 'Body / Mind / Spirit' theme will continue and may include sessions such as:

- Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- Latest orthotics, aids and equipment displays
- Chair yoga and meditation sessions
- Activities to keep the mind active
- Creative workshops
- Soul-searching sessions exploring various aspects of the 'Spirit'
- Massage and pamper therapy available

See Retreat details at www.polioaustralia.org.au/retreat-2017/

Polio Australia's Health and Wellness Retreat

26th - 29th October 2017

Approx. cost of registration fees for 3 nights accom, all meals and most activities \$350 pp double and twin / \$450 single / small group sharing options will also be available.

All fees yet to be confirmed.

Please provide me with more information on the Polio Health & Wellness Retreat when available.

Name:		
Address:		
Phone/s:	Email:	

Return to: Polio Health & Wellness Retreat, Polio Australia, PO Box 500, Kew East, VIC, 3102 or

Email: office@polioaustralia.org.au