



Volume 1, Issue 2



Polio Oz News

September 2011—Spring Edition

Post Polio Syndrome—A Challenge of Today

European Conference on Post Polio Syndrome

Copenhagen, Denmark
31 August to 2 September 2011



by **Mary-ann Liethof**
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This conference was jointly hosted by the European Polio Union (EPU) and The Danish Society of Polio and Accident Victims (PTU). The

conference focussed on the challenges that polio survivors experience the world over as they are aging with the late effects of polio (LEOP). There was a total of 330 participants from 25 countries.

Much of the conference was divided into two streams: one for polio survivors, and one for health professionals. This format was designed to provide leading researchers and experts in the field of post polio with the opportunity to exchange new research results and management strategies with health care professionals on a professional level, with the hope that the information will be distributed to the health sector in their respective countries. Most of the presentations were duplicated for polio survivors to ensure they also had access to the latest research, as well as strategies on assessment, treatment and coping. The collective presentations on Day 3 encouraged both health professionals and polio survivors to work on increasing the awareness of the LEOP within their political sectors.

Below are some of the highlights from my visit to Copenhagen and the conference:

Tuesday 30 August

I visited the [The Danish society of Polio and Accident Victims \(PTU\)](#) and was joined by fellow Australians Dr Nigel Quadros (Rehabilitation Specialist), Dr John Tierney (Polio Australia's National Patron) and Pam Tierney (John's wife). Our hosts were Britta Gnutzmann-Quistgaard, Head of PTU Rehabilitation Centre, and Lorne Larsen, Deputy Manager and

Physiotherapist.

The PTU has been operating for more than 60 years and *"works for equal conditions and increased quality of life for the more than 100,000 Danish people who suffer from serious injuries after an accident or a disease"*. Britta was saying that of the 1300 people accessing their rehabilitation services, more than 850 (65%) are polio survivors. The remaining groups targetted are people who have been injured in an accident, people with spinal cord injuries, and whiplash injury.

The Rehabilitation Centre employs 60 people: specialty doctors, psychologists, social workers, physiotherapists, occupational therapists, dieticians, orthopaedic engineers (orthotists), and swimming teachers. In addition to these multidisciplinary services, the PTU has a wonderful hydrotherapy pool, does vehicle modifications, and has its own driving school tailored for people with a disability.

Another impressive service is the opportunity for an intensive 3 week rehabilitation stay in the PTU's specially equipped apartments.



L-R: Britta Gnutzmann Quistgaard, Lorne Larsen, Mary-ann Liethof, John and Pam Tierney

Conference Details

- ◆ [Abstracts](#)
- ◆ [Final programme](#)
- ◆ [PowerPoint presentations](#)
- ◆ [Poster presentations](#)
- ◆ [Videos](#)
- ◆ [Photos](#)
- ◆ [Summary](#)
- ◆ ["Daily Danish Doings" Blog](#)

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From the President

Gillian Thomas
President

Welcome to the second issue of Polio Oz News which is once again packed full of great information for polio survivors, their families and carers, and health professionals alike.

In this issue I am seeking your assistance towards Polio Australia becoming financially self-sufficient. Naturally every donation, no matter how small, helps us to achieve this goal, but we are particularly seeking help from you for leads, and if possible personal introductions, to individual philanthropists, philanthropic organisations and

corporate bodies with whom we can establish mutually-beneficial partnerships. Supporting Polio Australia on an ongoing basis will make a real difference to the quality of life of Australia's polio survivors and their families – the "simple" task we have set ourselves is to identify partners who will work with us towards this end. We are sure that with the large readership of Polio Oz News there are those amongst you who can help out in this regard. Please see the article on page 19 for further information and I look forward to hearing from you soon.

From the Editor

Mary-ann Liethof
Editor

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Earlier this month I was fortunate enough to travel to Copenhagen, Denmark, to attend the European Conference on Post Polio Syndrome. As the only paid worker for Polio Australia, it was both important yet difficult to go. Important because of the need to learn what progress is being made in relation to management techniques for polio survivors and to network with other organisations; and difficult because there is so much work to be done for Polio Australia, as well as the fact that we had to carefully consider the cost of me attending due to extremely limited financial resources. Although Polio Australia regularly applies for project funding to run our programs, philanthropic trusts are not interested in paying for people to attend conferences! However, it was a very worthwhile trip, and I know the information presented

will be of benefit to many people.

But now it's back to the business of Polio Australia! As you will read in this edition of "Polio Oz News", nothing stands still in the world of Polio. As we are approaching October's Polio Awareness Month, now is the time to consider how you can raise awareness in your local community – especially amongst the medical profession – about the fact that polio survivors are "still here" and needing post polio-specific health services more than ever!

We hope you enjoy this edition of "Polio Oz News" and Spring's promise of better weather on the way!

**"Coming together is a beginning;
keeping together is progress;
working together is success."**

Henry Ford

Post Polio Syndrome—A Challenge of Today (cont'd from P1)

PTU's residential service is quite unique in Europe and is now being offered at a cost to people from other countries. The PTU has approximately 6,000 members made up of people with disabilities and their family members, who pay 250 DKK (approx. AU\$50) per year for membership. This membership entitles them to a range of services including: counselling, information/bimonthly magazine, advocacy, seminars and activities, and the use of a holiday house.

Britta is now juggling the services and space through a major renovation of the facility which should be completed in May 2012. This will give them considerable extra room and a more effective use of the existing areas.

We were all very impressed with the work of the PTU and took away many ideas for the type of services we would like to provide for polio survivors in Australia.

Wednesday 31 August

Day 1 of the Conference was highly charged with 330 polio survivors, their families, and health professionals all gathered to discuss Post-Polio Syndrome (PPS). I met people I had only known in cyberspace like Joan Toone, President of [Post Polio Awareness and Support Society of British Columbia \(PPASS BC\)](#), Canada, and Johan Bijttebier from the [European Polio Union \(EPU\)](#), as well as old friends like Joan Headley from [Post -Polio Health International](#), Ramesh Ferris ([Cycle to Walk](#) for polio

eradication), and Niels Frandsen ([The Epidemic](#) film) (*pictured below left*).

The proceedings commenced with a welcome from the respective Presidents of the PTU and the EPU, followed by musical entertainment from a young local performer and polio survivor, originally from Afghanistan. Then we had an update from Rebecca Martin from the World Health Organisation on the progress of the eradication of polio; Rotary's story behind the polio eradication program; and an overview of PPS by Frans Nollet, MD.



There was also a large display of orthotics equipment, some of which I hadn't seen before such as the wrist and neck supports.

After lunch, the topic of most interest to me was on the research being conducted in Sweden by Dr Kristian Borg with Intravenous Immunoglobulin (IvIg). Polio survivor Esther Boserup spoke about her personal experience with the IvIg treatment and how it improved her general condition and dramatically improved her quality of life. This was echoed by a few of the other polio survivors who had also taken part in this treatment trial.

The treatment consists of 900ml of immunoglobulin drip-fed intravenously over a 4 hour period, 3 days in a row. In the following 2

weeks, Esther reported that her mental and physical tiredness decreased considerably and the heavy 'fog' in her head decreased. She said her pain ceased and the muscles became stronger and responded better to exercise. The effects of this treatment lasted for approximately one year before dropping off. Two years later, Esther says she is back to where she started, but is about to have another treatment soon.

The IvIg treatment is still in the experimental stage, is very expensive and not available to everyone. Dr Borg also explained that 1/3 of people responded to the treatment very well, 1/3 only marginally, and 1/3 had negative reactions. However, he is now able to identify and treat those polio patients who fall into the first 1/3 category. This has potential for many polio survivors but may still be a few years off. Read more on Page 13 of the Abstracts [here](#).

Thursday 1 September

I gave [my presentation](#) today, hot on the heels of [Ramesh Ferris](#). Ramesh is a real showman and had the audience eating out of his hands. A tough act to follow, I can tell you. My presentation was on Australia's Health and Wellness Retreats, and when I'd finished I was approached by the National Vice President of Italy's Associazione Interregionale Disabili Motori onlus who wanted a copy of my presentation and anything else I could provide on the Retreats, and one Danish woman was very interested in attending our next Retreat in Queensland. Over dinner, Joan Toone from PPASS was also talking about organising a Retreat in British Columbia, Canada. It was very confirming that other organisations thought the Retreat format was worth exploring in their own countries.

Two separate research presentations that I thought would benefit from a joint approach were Dr Jülide Öncü's "[Disuse osteoporosis in the patients with](#)



Post Polio Syndrome—A Challenge of Today (cont'd from P3)

post polio syndrome" and Dr Alice Bickerstaffe's "Falls among polio survivors. Both concluded that "Falls are a clinically important problem for polio survivors". Öncü's study focused on hip fractures whereas Bickerstaffe's patients had less severe outcomes. However, Öncü referred to the extensive research which has been done on the relatively high mortality rate due to complications shortly after a hip-fracture-related hospital stay. To my knowledge, no specific research has been done to identify the morbidity rate of *polio survivors* due to complications from hip fracture but looking at these studies, one can only assume this is an additional and somewhat hidden problem for the polio community.

I was also very interested in a presentation by Dr Lise Kay, a Urologist at the PTU, who talked about 'Voiding and bowel problems'. This is not a subject that people really like to talk about, even though it can have such a large impact on their lifestyle. Lise said that people with post-polio syndrome have a higher risk of experiencing incontinence than others due to nerve and muscle function problems. Lise believes that there are many management strategies that can be implemented to help relieve these symptoms and people should see their doctor if symptoms have arisen within the last 1-2 years. Read more about this topic in Jill Pickering's "Just a Wee Story" on Page 5.

One of the wonderful services they had at the Conference was a booth full of interpreters who were turning the English presentations into French, German, and Danish. I've never actually seen this in action but it works very well in the European context. People are provided with a headset unit from which they can just select their specific language channel for almost instant translation.

Friday 2 September

This morning we only had two sessions where polio survivors

were separated from the health professionals. I don't fall into either of those categories but as a community development professional, I chose to hang out with my 'community'.

We were treated to information on orthosis management and information on the latest, light weight carbon orthoses. The crowd had been thinning with each successive morning so there weren't nearly as many people present as there were on Days 1 and 2. We all know that orthotics is a major consideration for so many polio survivors. However, we already covered the issues with fatigue, so no surprises there.

The combined afternoon sessions were getting down to the nitty gritty of clinical models, research factors including "The value of investigating patient perspectives". Well, OF COURSE! I suspect this was aimed at the health professionals but, in all honesty, they would have been preaching to the converted. All the health professionals who participated in the conference are already on board with this concept. Now we just have to figure out how to take the message to the wider audience. It was gratifying to note the number of eminent and well published medical professionals present, so it's not that the information isn't actually available, it's just that we need to be constantly pushing our respective health professionals to read up on it! (Talk about fatiguing!!)

Dr Jan Lexell from Skane University Hospital in Sweden talked about the interdisciplinary teamwork being carried out at his PPS clinic. They have a team consisting of a Physician, Nurse, Occupation and Physical Therapists, Social Worker and Psychologist. I can only assume they refer to respiratory specialists, orthotists, speech pathologists, and dieticians who are also important members of the late effects of polio management 'team'. Both Sweden and Denmark (maybe other Scandinavian countries as

well?) are funded to provide PPS clinics. I asked Dr Lexell if he believed working with polio patients differed from rehabilitation work with other patients with physical disabilities, i.e. stroke, etc. He replied that it was important to have specific knowledge/experience of the late effects of polio. From an economic perspective, health funding in Australia is always being stretched to cover as broad a base as possible. The consequence of this is the 'one stop shop' model where what is offered are generic clinical services with no specific expertise. This is clearly not serving the needs of Australia's polio survivors.

The last session focussed on the "Cost Effectiveness" of providing services for polio survivors and the need for more research in this area.

After the conference, some of the delegates went on a sightseeing tour so I finally got to see The Little Mermaid. I also met a young German man, Rudi Vallaster (pictured below with wife, Sandra). I hadn't noticed Rudi at the conference so when I saw him on the bus, I was curious about where he had contracted polio. Rudi told me that he had vaccine-associated paralytic poliomyelitis (VAPP) from



Post Polio Syndrome—A Challenge of Today (cont'd from P4)

his third dose of the oral polio vaccine (OPV) in 1976 at the age of 2.

The risk of this happening is 1 case per 750,000 but considering the number of children who were being vaccinated, there are obviously a number of other younger polio survivors in the Western world who contracted VAPP. Since 2005, Australia (in line with other Western countries) has been using the intravenous polio vaccine (IPV). This is a polio population which we don't often consider but should.

There were so many (mostly excellent) sessions packed in to this conference it was really challenging to take it all in. The presentations have been uploaded to the polio conference website so at least they can be digested a bit more thoroughly.

My feedback included the fact that there were no actual workshop sessions whereby people could break into smaller groups to brainstorm ideas and exchange specific information. Of course, a lot of networking was done informally during the breaks but people did naturally tend to

gravitate to those with whom they were more familiar. I would have liked the opportunity to sit around a table with around 10 people, both polio survivors and medical professionals, to brainstorm things like the best way to raise awareness amongst the medical professions, or whatever. This would have enabled people to share their own considerable knowledge and to network with people they may not have met otherwise. There were 330 people, after all! It was also a long time to sit and listen to people presenting 4 PowerPoint presentations in a row (approximately 12 each day) without being able to stretch in between. The chairs were typical of conference venues – uncomfortable and no arm rests . . . People were free to get up and leave the sessions whenever they wanted, but many of us don't just in case we miss anything.

I was also talking to the husband of one of the polio survivors who felt that the family members/carers had been totally unrepresented.

It's always a challenge to ensure participants have access to as much

information as they want. However, most of us left feeling like we had been part of something special and unifying.

The EPU is anticipating having another European conference in 2 years, with the most likely host city being Amsterdam. Polio Australia is also considering the possibility of holding a conference in Sydney in 2014 and would seek to include the Asia and South Pacific regions. Many of the European participants thought an Australian conference would be a great opportunity to visit our country.

To read more about my trip to Copenhagen, including photos, view my daily blog, click [here](#) (starting from the bottom of the page and work up).

See more about the conference and view the presentations given [here](#). 🌟



Just a Wee Story

by Jill Pickering

I had poliomyelitis in England in 1955 and was diagnosed with Post-Polio Syndrome (PPS) and the Late Effects of Polio (LEOP) in 1995. Since then I have almost mastered the art of management and pacing strategies to minimize increasing weakness and fatigue. However it was a total surprise to find one day when walking inside after sitting in a car for several hours that I was unable to stop wetting my pants. I had noticed my toilet visits were more frequent, with diminishing results, but put it down to my mother saying 'never miss an opportunity'.

I thought this may be a once off and vowed to toilet even more



frequently. Unfortunately I could not 'stem the tide' pardon the pun and for a year wet my pants about every 3 months. I discussed this with my GP, who has some understanding of PPS issues, and was recommended to have a urinary tract ultrasound before being referred to a Continence Clinic at Caulfield Hospital.

My 90 minute assessment appointment arrived soon along with a 48 hour urinary flow chart to fill in. The chart was like a time sheet, one hour time slots across for 48 hours and down columns to record the mls of fluid passed vs. my fluid intake mls. The hardest part was finding a receptacle to measure the outgoing mls. I eventually used a plastic fluid jug

which was deep enough to contain the mls and narrow enough to squeeze between my thighs and the toilet bowl without spilling...

My assessment was conducted by a Continence Physiotherapist at Caulfield Continence Service, Caulfield Rehabilitation Hospital, 260 Kooyong Road, Caulfield (Victoria) - Phone (03) 9076-6102. The assessment room had desk 'bladder' models to aid explanations. My first question was to ask if the physio knew of Polio or Post-Polio - the answer was a little since she had two other Polio patients and was becoming more aware of specific PPS management issues, such as increasing weakness and fatigue.

Just a Wee Story (cont'd from P5)

The bladder 48 hour record showed my expelled fluid mostly paced with my fluid intake, and toilet visits ranged from 90mins - 4 hrs. My urinary tract ultrasound showed a largish fibroid that reduced bladder capacity and that I did not fully empty. Fortunately no life threatening problems were noted.

Once on the bed, the physio put an ultrasound over the bladder and turned the screen so I could see clearly the pelvic floor muscle contraction that occurred when I tried to activate my bladder muscle. It took me a few minutes to work out how to operate the pelvic floor muscle and then it only moved a bit. In true PPS form, the 'move' diminished to a flicker over 6 contractions.

Bladder management techniques discussed:

- Stop – concentrate – use distractions to reduce the urge until a toilet is reached
- Lifting the belly to reduce pressure
- Reduce bladder irritants like coffee, rapid intake, anxiety or hurry (hard with an urge)
- Increase ability to fully empty the bladder by leaning forward slightly when sitting on the toilet, i.e. elbows resting on knees as this gives the urine a straighter path

Caulfield Continence Service handouts included:

The normal Bladder – functions as a reservoir to store between 350 and 500 mls of urine. The bladder has two phases – filling and emptying. The kidneys constantly filter urine into the bladder gradually filling it. During filling, the bladder, which is made of muscle, should remain relaxed and slowly distend (expand) to a point where you become aware of a sensation of fullness. It is normal to be able to put off urinating until a convenient time and place is found. When you are ready to pass urine the bladder should squeeze to empty itself completely – the emptying phase. Then the filling begins all over again.

What goes wrong – Urgency and accompanying urinary leakage may be due to an 'over reactive' or 'irritable' bladder which may want to empty even when not very full. You may feel as though you are 'busting' but when you get to the toilet there may not be much urine to pass. There are many reasons why a bladder may become 'irritable' e.g. infection, poor bladder habits, poor fluid intake, constipation. Sometimes we don't know the reason why.

Bladder training – Involves learning techniques to help you to 'calm the bladder down'. The aid is that your bladder will, eventually, squeeze to empty only when you are quite ready for it to happen and will hold larger volumes of urine. This may take time, patience and determination. You should expect 'good' and 'bad' days for a while. Learning pelvic floor muscle control is essential to success.

Other approaches – If bladder training is unable to help sufficiently, there are some medications or electrotherapy that may assist. (After discussing these options I felt they were not for me, i.e. they included muscle relaxing options but my problem was trying to get my muscles stronger.)

My Bladder Homework

- To practice three times a day contracting my pelvic floor muscle
- Try to reduce the urge and increase my time between toilet visits
- Lean forward, keeping the back straight, when I expel urine
- Drink smaller amounts of fluid more frequently
- Next appointment in 6 weeks to discuss the homework experience.

My Bladder Show bag

I was given a card for my next appointment with my continence physio, a range of contact details, and told I could email/ring with queries in between appointments. I was also given a small, tastefully pretty bag with continence pads ranging from thin 250 mls to large knicker style pads. Unfortunately

the maximum held was still only around 250-300 mls.

Summary

I felt the time allocated for my initial assessment was sufficient to cover all issues I wanted to raise in a relaxed manner, with an approachable therapist who seemed to have good understanding of how to manage continence issues and some understanding of PPS issues. I also felt I had been given some techniques to work on over the next 6 weeks, and back-up for longer car journeys where I may not be sure of stopping for an accessible toilet in time. I will write after my next visit about progress and any further options to consider if my pelvic floor muscle fails to increase control over exiting fluid. 🌈



Using a Segway: The Highs and Lows



Model on Segway

by Dr Ian Neering

I've always had a bit of a horror of wheel chairs. As Seinfeld would say "Not that there's anything wrong with wheelchairs" and that's true, but for me they have symbolized a form of capitulation to my old polio condition. This of course tended to work against me and caused a gradual closing in of my activities. I went to museums and galleries less frequently as walking became an increasing effort. I stopped going camping and in general my ability to get out, socialize and appreciate the outdoors dropped off significantly.

The physiologist in me told me that if I had a wheel chair I would walk less (even though I was already walking less!) and thus further weaken my walking muscles. Further, by sitting in a wheelchair, my bones would be doing less load bearing and this would accelerate the process of osteoporosis.

Despite all this drawing in of my physical world I was unwilling to actually do anything about it. The changes had been so slow that I had adapted to this altering lifestyle without really realizing it.

The penny finally dropped when it became too difficult to take our

beautiful Golden Labrador, Winnie, for her walks. I needed to do something to get mobile.

I had heard about the Segway shortly after it was released in the US in 2003. It was billed as the first self-balancing, electric-powered transportation machine. It uses five gyroscopes and a built-in computer to remain upright and seemed like an attractive way to get around. The speed and direction (including stopping) are controlled by the rider shifting weight and a manual turning mechanism on one of the handlebars. The initial public demonstrations showed that the Segway could travel smoothly across pavement, gravel, grass, and small obstacles. Best of all, you stand upright on the thing.

I lusted over the Segway for a few years but did nothing about it until a combination of circumstances - my lack of ability to accompany Winnie on her wanderings and the establishment of an Australian agency for Segway - tipped the balance.

Using a Segway is actually quite easy. The key is to relinquish control to the technology. For some, that's not always easy to do. My observation has been that the fittest, most sporty of my friends are the ones who have the most difficulty making the adjustment. They can't stand back and let the machine do the work. The slobbs including myself seem to do better. The key is to trust the machine. Let it do the work of staying upright. It seems counterintuitive that a two-wheel device can safely move you along with such little effort but if someone like myself with poor balance and weak muscles can drive it then anyone can do it. If you can stand still for any period of time, then you can ride a Segway.

To say that the Segway changed my life doesn't really give you any indication as to the way my daily appreciation of living improved.

Winnie, who is wonderfully trained and needs no leash outdoors, would be right by my side as soon as she heard the little bleep emitted by the Segway as it boots up. Off to the cupboard for a supply of treats and we're out the front door and galloping along at 15km/hr or so (the Segway can do around 20km/hr and has a range of around 20-30kms on a single charge of its batteries). Winnie charges through the bush flushing out rabbits while I stick to the bike paths that we're lucky to be endowed with in Canberra.

I am able to zip down to the local shops, enjoy the sunshine and fresh air, and the beauty of the Segway is that I can zoom straight inside, navigate the aisles to find what I need, taking up about as much space as a normal individual on foot. This works just as well in galleries and museums where I can manoeuvre like one of the throng with the added advantage that I'm a bit higher up due to the platform of the Segway.

The only disappointment is that the Segway, weighing in at around 50kg, is heavy to lift into the car and needs two normal slobbs or one really strong hero to lift it. I made a ramp with a couple of aluminium sections to facilitate loading but the result was pretty cumbersome and not really a convenient solution to the problem.

The other thing about the Segway is that over time it becomes intuitive to operate. Just like a car or motorcycle it becomes an extension of your own body and you integrate with it completely. This sounds good but it can become a problem as you will see.

Over the years poor Winnie suffered a common Labrador affliction, namely arthritic joints, and she slowed down considerably. Where once she would be leading me dashing from rabbit hole to water puddle, now she plodded doggedly along taking her time with long pauses to appreciate the smells along her route. This

Using a Segway: The Highs and Lows (cont'd from P7)

became rather boring for me, as I would move ahead and then return to exhort her to move along - or wait as she poked and prodded slowly up some byway in search of new olfactory stimulation.

To amuse myself while waiting for her, I would do "manoeuvres" on the Segway. Here's where that human integration with machine can lead to dangerous overconfidence.



Such manoeuvres might involve navigating a difficult or narrow section, making speed turns or other envelope stretching operations. I don't know many old polios but I suspect most of us like to test our limits and I have to plead guilty as charged. In the three previous years of Segway ownership I had become complacent. I had never had a fall off the machine but on this particular day, things were about to change.

There was a very enticing circular driveway inviting me to charge it at top speed bearing around in a tight arc. Unfortunately, part of it was lightly covered with loose sand. One thing about the Segway is that it is an intelligent device. It depends upon input from each of its two wheels. The internal computer matches up the feedback and adjusts the motors' output. The bad part about this is that if one of the wheels loses traction then the feedback is thrown out of kilter, which is a pretty good description of what happened to me. One moment I was a bit like Toad of Toad Hall, enraptured by the speed of his car (parp, paaarp!!) and the next I was sailing through the air sans Segway, which appeared to be flying over my head. At least, something was flying over my head which was itself flying.

The resulting impact with the ground proved to be quite painful. I

lay in the sun pondering my situation. I could move quite well but moving seemed unadvised as there were various parts of my chest and back that felt as if they'd been shifted around inside me. Winnie took interest in this new situation and came up for a consultation. I suggested to her that she get some help but she thinks Rex is a show-off and has failed to accept him as a role model. It was mid afternoon in a quiet suburban Canberra street. Not a soul about. Winnie would wander briefly away, sniff at some old dog droppings and then return to give me an encouraging lick. Then she would retire to the shade and watch over me as I slowly baked in the hot sun. After about 25 minutes a car did come along and the driver called an ambulance for me.

Here, in my Segway eulogy, I'd like to digress briefly to make a few medical points.

Many of you who read these newsletters will be aware that the medical and para-medical professions aren't always aware of what is good for us old polios. When the ambos arrived, one of the first things they did was give me a dose of morphine despite my exhortations that this was a bad idea. I wasn't in agony and I was concerned about the respiratory depressant effects of the morphine on my breathing. Because of my physical deformity, my lung capacity is very low. Anything that further compromises my breathing should be considered as risky. I guess because the ambos are trained to follow a uniform protocol, they ignored my request. This needs to change.

I won't go through the details of the ensuing sequence of events but I ultimately woke up in the netherworld of an intensive care ward with an endotracheal tube down my throat attached to a ventilator to support my respiration. I was completely paralysed and could barely open my eyes. The paralysis was due to the effect of repeated doses of

neuromuscular blocking drugs, which are necessarily used to assist the intubation process. Old polios are particularly sensitive to these drugs and lower doses than normal should be used as it may exacerbate muscle weakness for days. This, most assuredly, slowed down my recovery.

The third issue arising from the accident relates to the way that old polios are adapted to their existing physical condition. My fall resulted in broken ribs and a haemo thorax or bleeding within the lungs. This accumulation of blood means that the lungs can't function normally and gas exchange - uptake of oxygen and blowing off of carbon dioxide - can't take place as efficiently as it should. Hence, the need for artificial ventilation until the blood can be drained from the lungs. To evaluate this process, the intensive care physicians regularly measure the blood gas concentrations and when they're back close to normal, they take out the endotracheal tube. In my case, as a result of pre-existing chest deformity and respiratory muscle weakness my blood gases especially carbon dioxide were already "abnormal" before the accident. However, my body was well adapted to this apparently abnormal situation and able to function perfectly well. The intensivist, unaware of this situation was unwilling to remove my tube. This is dangerous because the longer one remains on artificial ventilation, the more difficult it becomes to wean the patient off the artificial support. The problem arises because intensivists work "by the numbers". If those blood gases aren't by the textbook then you ventilate until they are. For old polios, this is plain wrong. Luckily my old friend and colleague Simon Gandevia made a special trip to Canberra to explain this to the intensivists and the tube was pulled.

I'm back on the Segway now albeit with much more respect and caution. Segway head office in the



Using a Segway: The Highs and Lows (cont'd from P8)

USA were keen to get full details of the accident. To their great credit, they agreed to ship the Segway back to the USA, examine and repair it for me and return it, all free of charge. I should stress that this accident was my fault entirely and there is no evidence of any malfunction by my Segway. Like all mechanical devices, if you are going to ride it, you need to be aware of its limitations. I would have no hesitation in recommending a Segway to those of you who feel capable of riding one. I can assure you that you will enjoy the ride.

A word of caution however: If you are interested in trying out a Segway be informed that the latest models do not have stable, vertical support for the handle bars as my older model does. The newer

model allows you steer by leaning the handlebars to one side or other as opposed to the twist hand control located directly on the handlebar that existed previously. This would not be feasible for me to use as I depend on the rigid upright to support myself.

A final issue that needs to be considered is the legality of the Segway. While in many European countries and American states the Segway is permitted, as far as I am aware, their use on Australian roads and footpaths is considered illegal. This apparently even applies to their use as scooters for the disabled. Not that I or anyone I know who uses a Segway has ever been admonished by the law but it's something you should be aware of. This would seem to be rather short-sighted of our

regulating authorities given the rapid development of these vehicles and the general efficiency of electrically powered devices. These new vehicles under development such as the Toyota Winglet and the Honda U3-X resemble the Segway in operation but are much lighter and thus promise to be more portable and easy to manage. It might be an opportune time for some local activism to get some of these devices accepted. 🌐

Ian was Associate Professor in Pharmacology at UNSW. He "retired" around 1996 and currently, with his business partner, runs Mount Sylvia Diatomite, a small mining and manufacturing operation in SE QLD.

How I became National Patron of Polio Australia



by Dr John Tierney

Twenty years ago I was required to make a speech to convince a political party that

they should select me to represent them in the Australian Senate instead of one of the 32 other candidates for the position.

I won the preselection by one vote with a speech that, at its core, told the story of how contracting Polio just after birth (1946) had shaped the rest of my life.

Having been born into a family of high achieving athletes (my eldest brother ran with the Olympic torch in the 1956 Melbourne Olympics), I quickly concluded by the age of 5 that sport was not going to be my thing. At the 1950 South Coast District Sports Carnival, I ran in the 5 year old foot race with a calliper

on my left leg, coming a distant last. When I retired from the Senate in 2005, I received a letter from one of the parents who watched me 'run' that day. He wrote: *"you came last in the foot race, but first in the hearts of all the people who watched you run."*

As I was growing up I decided to focus more on my brain than my body, developing an increasing fascination with the world of ideas and in my late teens became increasingly drawn into the world of politics. By the time I reached my mid-forties, my driven A-type personality (typical of Polio survivors), had taken me from a university senior lectureship into the Australian Senate where disability policy was one of areas that I focussed on.

At about this time, the first signs of the Late Effects of Polio (LEOP) were starting to affect my mobility. In 1994 an MRI scan revealed spinal stenosis, scoliosis, arthritis, three large lumbar region spurs in the spinal canal and five severely damaged lumbar disks. An

Osteopath who later looked at one of my MRIs said, *"boy are you a mess."* I was told I would need major spinal surgery by 2004. This year they are now saying maybe surgery will be necessary by 2014. I believe that the reason I was able to move this rather drastic surgical step from a 10 to a 20 year time horizon was through better self-management of the LEOP. This meant that to achieve my goal of slowing down the inevitable physical degeneration that occurs with the LEOP, a radical change in lifestyle was required in the way that I physically did everything.

I spoke about the LEOP in a Senate "Matters of Public Interest" speech (2005) where I outlined how this condition was affecting my life and the importance of self-management of the LEOP. The next day Polio Australia's President, Gillian Thomas, read this in the Hansard transcript (as you do) and contacted me. At that stage I was completely unaware that state Polio networks existed for Polio survivors but jumped at the opportunity to learn more. I have

How I became National Patron of Polio Australia (cont'd from P9)

attended every LEOP seminar and Retreat that I have been able to get to, including the international ones (Warm Springs, USA, in 2009 and Copenhagen in 2011). Although I have heard the same things covered a number of times, I always take away from these sessions something new and useful for the self-management of my condition.

I became very involved in the work of Post-Polio Network (NSW) (PPN) from 2005 and subsequently the inception of Polio Australia in 2007, with my main contribution being my skills as a political lobbyist. Up until my retirement last May at the age of 65, I was a Partner at

Government Relations Australia Advisory (GRA) which is Australia's largest bipartisan lobbying firm. GRA had generously allowed me to do pro bono lobbying work for a number of charities including Polio Australia and PPN.

Lobbying in Canberra for people with the LEOP has been quite a challenge. The team from Polio Australia includes me, Gillian Thomas (President), Neil von Schill (Treasurer), Mary-ann Liethof (National Program Manager) and Peter Garde (Carer/PPN). When our lobbying team first went to Canberra in 2007, we were greeted with comments such as, "*didn't we fix Polio 50 years ago?*" We have

gone from zero recognition of the LEOP to having four Parliamentary Patrons and a "*Parliamentary Friends of Polio Survivors*" group in Canberra. A change in the Federal Government's health policy last May means that over the next year there is a very good chance that we will receive funding for some of the programs that our Polio Australia team has been lobbying for so hard.

Last year I was asked to become the National Patron of Polio Australia. It has been an honour and a privilege to accept this position and to work with such a highly professional and hardworking team. 🌟

Physiotherapy Management of Polio Survivors

by **Melissa McConaghy**

Jan came to see us at our Polio Clinic (based in St Leonards, NSW) because she had started having several falls, one of which fractured her left patella. She was also getting quite severe lower back pain that was starting to interfere in her work and home life. Jan had polio when she was four years old, at 53 she was still severely affected in the left leg and had never seen a physiotherapist having grown up overseas.

When Jan came to the clinic it was obvious immediately what might be causing her falling and what was causing her back pain. Jan had a leg length difference between her right and left leg of 5 cm and was not able to pick her foot up off the floor when she was walking. This meant that she walked with a significant limp and high stepping pattern to make sure that she could get her foot through without tripping. Over time, this difference had been causing an imbalance in the biomechanics of her spine, hips, leg load and stability. Orthopaedic problems are very common in our clinic, especially overuse strain, degenerative changes in the joints and the

resulting pain. These can all lead to a loss in mobility and independence as well as decreased confidence.

In our clinic, we were able to prescribe Jan a shoe build up and a simple foot lifting assistance device. The shoe build-up meant that she was now level at her hips which helped to unload her back and reduce her back pain significantly. Because of the big change in the leg length, we needed to monitor this closely and increase the use of the shoe gradually.

The foot lifting assistance device, called a [Dictus](#), attaches to the shoe and helps to clear the foot when it swings through. This helped Jan to walk with a more normal pattern without 'prancing' around as she said. We also prescribed an exercise program for Jan to work on her balance as well as back and posture control. Jan was concerned about her balance, even after we had reduced the risks of tripping, so we also advised Jan to use a stick for outdoor mobility, based on the scores she achieved in a balance assessment.

Jan has since started a hydrotherapy program at her local pool and has had a visit from our

Occupational Therapist to make sure that her bathroom, kitchen and bedroom are set up to make sure she is safe and independent at home.



Jan is fairly typical of the people who visit our centre with a past history of polio not being their primary concern. Treating someone with a history of polio is considered rare these days in the physiotherapy profession and for that reason we are now finding ourselves called upon to consult and advise other physiotherapists without the same level of experience.

Most of the questions we get both from clinicians and polio survivors are about exercise prescription, especially any relevant precautions

Physiotherapy Management of Polio Survivors (cont'd from P10)

to exercise. Prescriptions can be complex and need to be made in the context of the individual and their goals. Like other neurological conditions, many factors need to be considered in the prescription including factors such as pain, weakness, overuse strain, falls and fatigue. Sometimes prescriptions can even be made for people to stop exercising and take a break.

Physiotherapists work as part of a multidisciplinary team and play a large role in gait re-education following prescription of orthotics, equipment and mobility aids. Much of our work aims to keep people on

their feet as long as possible and as independent and pain free as possible.

So, if you haven't seen a physiotherapist lately or are finding activities and mobility difficult like Jan, contact your local post polio support group and get them to put you in touch with a physiotherapist familiar with polio. Keeping in touch with a physiotherapist who knows your condition can help you to be proactive about your physical health and maintain and often improve your quality of life. 🌟

For more information, contact the [Advance Rehab Centre Polio Clinic](#).



Melissa is a member of Polio Australia's Clinical Advisory Group.

Facing Surgery—Be Prepared!



by (Jega) Gnanaletchumy Jegasothy

One of the complications of ageing with the late effects of polio is that a number of Polio survivors will have to undergo surgery to various joints. Therefore, it is timely to remind Polio survivors to make sure that they are well prepared with information to give to their General Practitioner, surgeon, therapists, etc. More important is to *ask the right questions* and have all the information you need, **before the operation**.

It is not often obvious to others

how Polio survivors have adapted to:

- self care tasks like getting out of bed, getting on and off the toilet, personal hygiene management, showering, and dressing
- activities of daily living such as cooking, house cleaning, shopping and socialising

Questions you need to ask

Consider activities that you are involved in and consider how the operation will impact on these activities if you have to use an aid for a while. Obtaining answers to the following questions will give you information on how to prepare yourself for the operation.

1. Before the operation, ask the doctor about length of bed stay required. Inform the doctor/surgeon that inactivity will only weaken your muscles. If bed rest is required, you must be given a list of bed exercises to keep your muscles ticking over. Who will provide this list?
2. Ask the doctor/surgeon about:
 - the period of time you may require a walking aid. If you have had difficulty using a

walking aid, bring this up now.

- how much weight can you put on the operated joint or the operated limb?
 - what range of movement are you allowed? For example: sitting in a standard chair, sitting on a lounge chair, getting on and off the toilet, and getting in and out of a car.
 - who can you talk to regarding access to equipment you may require post-operatively?
 - who you can talk to regarding access to physical assistance or home help if you are going to need this post-operatively?
3. Discuss issues such as: whether your spouse is strong enough to help you; if you need help with moving in bed; getting in and out of bed; with self care; personal care activities; and walking.
 4. You might ask about assistance from an agency support worker for self care activities. You might also need assistance with house work and with shopping.
 5. Consider asking for an assessment of your home by an

Facing Surgery—Be Prepared! (cont'd from P11)

Occupational Therapist to look at assistive devices to help in the post-operative period till you are fully functional.

6. Find out about post-operative physiotherapy to regain strength and ensure that you are able to maintain independence.

7. If the operation involves a joint in your arm, ask your surgeon or pre-operative clinic team:

- how long before you are allowed to move the joint?
- how will this affect your self care ability and activities of daily living?
- what sort of splint will you be wearing?
- will you be able to remove and put the splint on by yourself, especially if the operation is to the stronger arm?
- if the operated hand is the stronger hand, are you strong enough to use a stick in the other hand?
- what will taking weight on your weaker arm do to your shoulder joint if you put extra stress on the joint?
- when can you start carrying objects in the operated hand and what weight can you carry?
- will you have access to physiotherapy or occupational therapy to regain mobility, strength and function in your operated limb?

8. If the operation involves the leg, ask your surgeon or pre-

operative clinic team:

- if you will need a walking aid?
- are the joints in your arms strong enough to take the stress?
- when can you put full weight on the limb?
- how much bend are you allowed at the operated joints? This will affect chair and toilet seat height. If you have steps in your house, you may have difficulties. The height of your bed may need to be looked at.
- how or where can you access equipment for activities of daily living? For example, you may need a shower chair to be able to shower safely.
- can you get a Physiotherapist and Occupational Therapist assessment of your home to assess how you normally do perform your daily activities and what environmental changes might need to be made? For example, if you rely on the momentum of the lower part of your body to swing out of bed, you might need a bed rail to help you sit up or move in bed as you might need to rely on arm strength for a while. Do you have enough space in the house to use a walking-aid? Do you have carpets that might make it difficult? Bring these issues up early.
- when will you be able to recommence driving?

Polio clients who are working or who are actively engaged in community work need to consider the impact of reduced mobility/ use of mobility aid on the way they resume their regular activities. For example:

- if you have a total knee replacement or hip replacement and have difficulty walking without an aid, a walking stick would resolve the problem. But is this possible if you are farming or working in a job that involves lifting or working as a volunteer driver?
- if you are unable to walk any distance, using a scooter or wheelchair would resolve the problem of distance walking, but is this compatible to your activities?

Always go to the doctor with written questions as we can all have 'performance anxieties'.

For those who are Internet savvy, "[Preventing Complications in Polio Survivors Undergoing Surgery](#)" by Richard L Bruno, PhD, is a good guide.

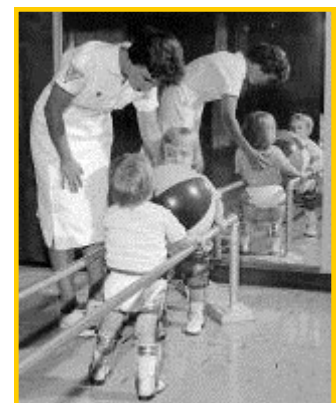
Sharing experiences and solutions with other polio survivors is also a useful way of problem solving. 🌐

G. Jegasothy is a Senior Physiotherapist at the Late Effects of Disability Clinic, [Royal Perth Hospital](#). Jega is also a member of Polio Australia's Clinical Advisory Group.

The Polio Crusade

The [Polio Crusade](#) will be shown on SBS One (in Australia) – Friday 23 September 2011 at 8.30pm

In the summer of 1950, fear gripped the residents of Wytheville in the US. The town was in the midst of a full-blown Polio epidemic. That year alone, more than 33,000 Americans fell victim . . . *Tune in this Friday* 🌐



The Australian Polio Register



The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 1360 polio survivors on the Register and this number increases daily, so please check our website often.

With limited resources to promote the Polio Register widely in the community we are nevertheless pleased with the results to date, however, we know there are many more thousands of polio survivors out there. To make the Australian Polio Register truly reflective of the unmet need for polio services throughout Australia, we urge every Australian polio survivor to join the Polio Register.

Our strength lies in our numbers – please help us to get you the services you need by completing the [Australian Polio Register](#)

form. If you have previously completed the form and given Polio Australia permission to publish your polio details, you can check your entry by [clicking here](#).

The polio details received from the many Australians who have already completed the Register will be reported on the website. The publishable data in the Register can be sorted in various ways (family name, maiden name, given names, birth year, polio year, age at which polio contracted, or location where polio contracted).

Note that both the numbers of polio survivors on the Register and the associated statistical data are updated dynamically as each new registration is recorded online. 🌐

October is Polio Awareness Month: We're Still Here!

Australia's Polio Community - forgotten and invisible

"We're Still Here!" is the catchcry of tens of thousands of Australians who contracted polio during epidemics between the 1920s and 1960s. There have also been a number of polio survivors who migrated to Australia from countries where polio was more recently eradicated, or is still active.

Unfortunately, establishing the exact number of Australia's polio survivors is incredibly difficult. Although polio became a notifiable disease in 1922, contemporaneous evidence during the epidemics last century and more recent State Network records reveal that many cases of polio were not reported. Reasons include people

being cared for at home, living in isolated areas, or the stigma attached to having contracted polio. In addition, many hospital records have since been destroyed due to practices at the time or as the result of hospital fires, moves, or closures.

There were also a large number of 'sub-clinical' cases – including siblings of polio survivors who had polio – who only experienced 'flu-like symptoms' and were never actually diagnosed with polio. Added to that are the number of people who were misdiagnosed with, for example, encephalitis or influenza.

Arguably, polio survivors form the largest single group of people with physical disabilities in Australia,

yet this is unrecognised by policy makers, the community at large, and indeed the polio survivors themselves. Polio survivors are to a large extent invisible in the community. However, many are now experiencing new symptoms known as the Late Effects of Polio which are having a significant and negative impact on people's mobility and independence.

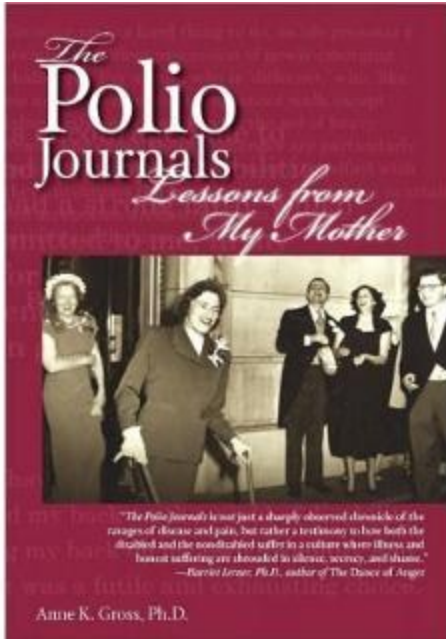
October is National Polio Awareness Month and Polio Australia encourages people to **"Wear Orange"** between the 9th and 15th of the month to show support.

Read more about [Polio Awareness Month](#) activities around Australia. 🌐



The Effects of Silence About Polio Across Generations

by Dr Mary Westbrook



A very interesting recent addition to the biographies of polio survivors is Anne Gross's book, "The Polio Journals: Lessons from my Mother". Some years ago in an article, "Early memories of having polio", I described how for many years polio biographies written by survivors or their families tended to be accounts of achievement through hard work and triumph over remaining adversity through cheerful acceptance. American sociologist Irving Zola, a polio survivor whose visit to Australia helped kick-start the foundation of the NSW Post-Polio Network, once said that the biographies of people with disabilities rarely "tell it like it is". Indeed he considered that "to a marked degree certain aspects of disabled people's lives have been inaccessible to themselves" for a variety of reasons which I explored in my article. With the advent of post-polio syndrome polio biographies have become more authentic and insightful e.g. Hugh Gallagher's "Black bird fly away", Anne Finger's "Elegy for a disease" and Patrick Cockburn's "The broken boy". Kathryn Black's book "In the shadow of polio" told of the impact on her life of her mother contracting polio when Kathryn was

a child. After several years in an iron lung her mother died, her father left and the children were brought up by their grandmother who could not speak of what had happened. "I never heard the words 'your mother' or 'polio' which only contributed to the shame, the mystery, and the abandonment of Mother's death".

Silence and shame about polio across three generations is the major theme in Anne Gross's book which tells the life story of her mother Carol who contracted polio aged two. The biography interweaves Anne's recollections of her mother and grandmother and Carol's own diaries with memories of people who knew Carol and her medical records. Anne writes about how shame and silence damaged Carol's relationships with other people particularly her mother and later her daughter. Polio left Carol with paralysed legs and very weak lower back and abdominal muscles. Despite physiotherapy, surgeries and three lengthy treatment periods at Warm Springs, Carol could only ever walk short distances using callipers and walking sticks. For most of her adult life she used a wheel chair and eventually an electric chair due to post-polio syndrome and failed rotator cuff surgery. Carol was pushed by her parents to excel in order to be acceptable to others. After college she married and had two children, worked successfully as a professional musician, later managed a community centre, was a member of a Californian task force on the International Year of the Disabled, then trained as a psychotherapist and worked with disabled clients, won a Woman of Achievement award, lived a comfortable life with servants, entertained famous people and owned holiday homes in Hawaii and Italy. In her fifties, following her training as a psychotherapist, Carol began to keep diaries in which she recorded her feelings about her disability.

This successful woman wrote, "I am always scared, I always feel weak and helpless ... I am not worthless, I am not pitiable, I am not one of society's abominations ... I insist on making it with the best of you. I need to every day, in order to validate myself". Carol left these "deeply honest and often harrowing" journals to her estranged daughter when she died from lung cancer in her sixties.

Anne describes how Carol's parents "colluded with the dominant view that her disability was a black mark on their family". Her mother "never touched [Carol] and she hated to look [at my legs]". The message was "become extraordinary in order to make up for what you really are - an awkward ugly cripple. Be smarter. Be more charming. Please everybody. Keep a smile on your face. Make people like you". Carol was frequently told that she "cost" more than other children, she was deserted during periods of hospitalisation, not permitted to socialise with other polio children outside treatment settings and punished in subtle ways for not being a "perfect" child like her brother. At the same time the family conveyed by their silence about her disability that it was inconsequential and should be ignored. When Carol's wealthy family moved to new homes no accommodation was made for her disability so in one she struggled up four flights of stairs and was given the least accessible bathroom. Anne believes that her grandmother's many "reprehensible and inexcusable" behaviours were "fuelled by her own guilt at 'causing' my mother to contract polio by allowing her to swim in the ocean and the self-hatred of having a daughter paralysed by polio. Unfortunately her same self hatred now defined her daughter". Carol's husband, who received an offer of considerable financial help from Carol's father prior to their wedding, adopted her parents' stance. Anne recalls that, "When I was growing up, my parents never uttered a word about my mother's

The Effects of Silence About Polio (cont'd from P14)

paralysis or the history behind it. If the word 'polio' was mentioned, my mother would look the other way, an angry expression on her face. I soon learned the unspoken rule in our house: we were never to ask about my mother's disability nor were we to think of our family, or my mother, limited in ways that others weren't". While her husband provided much physical assistance to Carol little account of her needs occurred e.g. he bought a three storey house without consulting her, he insisted on them maintaining a very active social life despite her increasing fatigue and disability and in the last years of her life ignored her requests and distress. Carol's silence and shame and lack of support from her own mother contributed to her poor relationship with her daughter. The concern that Anne as a child frequently felt for her mother was rebuffed. Carol was angry with Anne as an adult for not responding to her unspoken needs.

Anne writes that Carol's diaries record the "tremendous amount of relief she [felt] as she unlocked the shackles of denial that had imprisoned her" but communication

with her somewhat heartless husband and absent daughter did not occur. It was only when Anne read the diaries 18 years after Carol's death that she began to understand her mother's struggles. Anne concludes her memoir: "Although I was crippled for decades by her steadfast refusal to share anything about her experiences as a paraplegic, I had come to appreciate why it was impossible to do so. Sharing these memories would have risked the unthinkable - that she would be left alone, bereft of any connections to other people. My mother forged the only life possible given her circumstances - and in many ways it was a good life." 🌟

Mary is a member of Polio Australia's Clinical Advisory Group.

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Anne Gross's book is available from www.BookDepository.co.uk for \$A17.11, free delivery, and from Amazon.com (US\$16.95 plus delivery).

My Polio Story

by John Cosgrove

It had all started that Monday morning, John having woken feeling a bit seedy after playing in a tennis tournament the previous day. Unwell, he lay in bed for ten minutes trying to figure what he would teach each of his eight High School classes that day, what homework he had set and what books he needed to take with him to school. Finally, he stepped out of bed and, to his astonishment, both knees shot out in front of him and he crashed to the ground. Because his roommate had left earlier for work John had to painfully and awkwardly lever himself back to a supine position on the bed. Utter confusion followed, he had no idea of what was happening to him. His legs would not work!

Weakly he called until his landlady came bustling along the hall to see what was wrong. After a short conversation that good lady said, "I'll ring the doctor now" and she hurried off to do so. John was struck by a fear he had never known before, a terrible chill descended on his back teeth. Four to five hours later the doctor still had not come and, despite a swelling bladder, John could now not pass water, paralysis was spreading rapidly and no one whom the landlady consulted knew what to do. His friend Kevin had arrived, summoned home early and he was as mystified as the rest. There was a knock at the front door and, the next moment, an elderly doctor, himself breathing wheezily, popped in to the room. Questions and answers, prodding and listening, lifting and dropping legs followed then the doctor pronounced, "ring an ambulance, tell them it's urgent." "He can't pee", cried the landlady and he says he's busting." "I'll have to catheterize him now, before the ambulance comes, all out, wait outside", said the kindly old medic. John's eyes showed a little horror, this was startling new territory that he had thought he would never enter. That sense of invulnerability normally protects us all, "It can't happen to me." But it had. 🌟



John Cosgrove's complete Polio Story can be read [here](#).

A Retreat for Roosevelt in Georgia Burns Down



by Robbie Brown

Source: [New York Times](#)

11 August 2011

WARM SPRINGS, Ga. — It was the home where [Franklin D. Roosevelt](#), ravaged by polio, learned to walk with a cane and leg braces.

It was where he was persuaded by Democratic leaders to run for president in 1932. And it is where, whenever his health deteriorated, the future president would wade into the calm streams nearby or read books on the front porch.

But on Tuesday, the [McCarthy Cottage](#) — a wooden, six-room getaway that Roosevelt had built on a sprawling West Georgia property in 1927 and visited dozens of times during his New York governorship — [burned to the ground](#).

The fire's cause is unknown, but the police said it was probably a lightning strike or an electrical failure and did not suspect arson. The building was owned by the State of Georgia and was part of the [Warm Springs Historic District](#). In recent decades, it had been mainly a tourist site and a vacation home for prominent visitors, including Roosevelt descendants.

"Tourism is our economic engine," Mayor Sheila Lee said. "When it's something historic like this, it can't be replaced."

Roosevelt, a rising political star, began coming to Warm Springs in 1924 seeking a cure for his crippling polio. A friend told him that locals believed the dense, naturally hot streams had healing powers — something he believed until his death here in 1945, despite little scientific proof.

This town of 478, in what was once the poorest county in Georgia, became Roosevelt's unlikely home away from home.

In 1927, he bought 1,200 acres of property here, turning an existing hotel and cottages into a center for treating polio. The McCarthy Cottage — named for an acquaintance, the Canadian businessman Leighton McCarthy, whose son had polio — became Roosevelt's own residence. Between 1927 and 1932, he stayed there 18 times, for a total of 65 weeks, according to the [Roosevelt Warm Springs Institute](#), a state-run center for people with disabilities that now occupies the property.

He was there during many historic events, including the stock market crash of 1929. It is also where, historians say, the aristocratic Roosevelt was first exposed to extreme poverty, and it helped inspire his New Deal programs.

He continued to visit Warm Springs as President but stayed in a larger, separate home that

became known as the [Little White House](#), which receives nearly 100,000 visitors per year.

The fire began early Tuesday morning and engulfed the cottage and another nearby "like matchboxes with lighter fluid," said Gregory Schmieg, the executive director of the Roosevelt Warm Springs Institute. "In 15 minutes, it was all gone," he said. "I don't think there's anything anyone could have done."

Now local and state leaders are trying to decide whether to rebuild. All that remains is a brick fireplace, the stone foundation and rubble. Any replica might feel inauthentic, many worry. "There's a part of me that says, 'Out of respect, do we leave it as is, as a monument?'" Mr Schmieg said.

The original furniture was removed long ago. But HBO, which filmed [a movie](#) about Roosevelt there, left replicas of his bed and living room furniture. And there were some reminders of his disability, including the call buttons he used to request assistance.

"People ask, 'What's historic that's in that building?'" said F. Martin Harmon, the public relations director for the institute. "I say, 'The walls, the ceiling, the light fixtures, everything, because F.D.R. lived there.'" 🌟

Editor

In 2008 I visited Roosevelt Warm Springs Institute, together with travelling companion and polio survivor, Jill Pickering, as part of my Churchill Fellowship.

The Executive Director, Greg Schmieg, treated us to a tour of McCarthy Cottage, and we could clearly feel the history of the place. It was quite poignant.

It is so sad to think that this amazing opportunity to slip back in time will no longer be available to future generations. 🌟

Do You Know About TADAUSTRALIA?

Technical Aid to the Disabled Australia Inc ([TADAUSTRALIA](#)) is the national body representing state-based organisations whose volunteer members design, construct or modify equipment for people with disabilities, provided no commercially available product or service will meet their needs.

For example, TADVIC's volunteers make custom equipment for people with a disability throughout Victoria. This service helps people with disabilities for whom no commercially available solution exists. Founded in 1975 and incorporated in 1977, it operates

throughout the state of Victoria.

In general, occupational therapists coordinate projects with support from technical volunteers as required. Administration staff support the work of metropolitan and rural volunteers and staff. The organisation is funded by a grant from the Department of Human Services, Victoria, and donations. In recent years, in response to community demand, TADVIC has established 10 branches in rural Victoria.

TADVIC has around 200 volunteers throughout Victoria. In 2007 TADVIC completed over 620



projects across the state.

There is no charge for the service. Clients are asked to reimburse the volunteer for any cost of materials and travelling expenses incurred. Check for the TAD organisation in your state [here](#). 🌐

National Disability Insurance Scheme Update

I SUPPORT THE NDIS,
It's time to make every Australian count

TAKE ACTION

www.everyaustraliancounts.com.au

by **John Della Bosca and the Every Australian Counts team**

We were overwhelmed by the response from thousands of people from around the country, who sent our nation's leaders a strong message that we're counting on them to ensure that the NDIS becomes a reality.

The National Disability Insurance Scheme was high on the agenda at today's Council of Australian

Governments meeting in Canberra [22 August 2011].

Ahead of [this] meeting a wonderful group of campaign supporters met with Prime Minister Julia Gillard and her COAG colleagues to deliver a package from the campaign.

[You can see from the photographs](#) that they were enthusiastically received by your Premiers and Chief Ministers.

The message in those packs said:

"Today and over the coming months, Australia's disability community will be watching to make sure the long wait for proper care and support will finally be over. The first steps have been taken - but we know that for the dream of an NDIS to become a reality many more steps will need to be taken." [Read the full message here.](#)

You can read about the outcome from today's meeting here:

- [Prime Minister - Joint Media Release - COAG Delivers Key Step For National Disability Insurance Scheme](#)
- [Council of Australian Governments Meeting - Communique - Canberra](#)

After the most exciting and momentous fortnight of campaigning there is much to celebrate. But we also need to remember that there is a long way to go. It's important we maintain our vigilance and keep up our energy levels.

If your MP has not had a visit, now is the time to make that appointment and make sure they count. [Click here to see who has had a visit.](#)

If you haven't asked your friends to join up to the campaign yet, [tick that box today.](#)

Let's reach our goal of 100,000 supporters so we are in the best position to make sure the NDIS delivers for all Australians.

www.everyaustraliancounts.com.au

P.S. Keep up to date with all the campaign news [via the campaign blog](#). 🌐



Polio Health and Wellness Retreat in Queensland



Polio Health and Wellness Retreat

Body / Mind / Spirit

SurfAir at Marcoola, Queensland

Thursday 26, Friday 27, Saturday 28 and Sunday 29 April 2012

~ *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 from Thursday 26 to Sunday 29 April 2012 on the beautiful Sunshine Coast in Queensland. The holistic 'Body / Mind / Spirit' theme will continue and include:

- ◆ Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- ◆ Hydrotherapy and exercise options
- ◆ Latest orthotics, aids and equipment displays
- ◆ Seated Yoga and Meditation Sessions
- ◆ Activities To Keep The Mind Active
- ◆ Creative Workshops and Singing for Health
- ◆ Massage therapy

See details of previous Retreats at www.polioaustralia.org.au / *What we do / Self Management*

Polio Australia's Health and Wellness Retreat

26th April – 29th April, 2012

(Registration Fees for 3 nights accommodation, all meals and most activities = \$300 pp double / \$400 single)

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



Supporting Polio Australia

In our first "Polio Oz News", one of the articles reported on Polio Australia's achievements since the office was opened in January 2010. These include:

- Lobbying Federal Government for polio specific services
- Organising and running Polio Health and Wellness Retreats in New South Wales (2010), Victoria (2011) and preparing for Queensland in 2012
- Developing and launching Polio Australia's fact-filled [website](#)
- Launching the "[Australian Polio Register](#)" to capture important data about our polio community
- Running October's [Polio Awareness Campaign](#)
- Producing Polio Australia's monthly [e-Bulletin](#)
- Establishing a [Clinical Advisory Group](#) (CAG) to advise on the development of Clinical Practice Recommendations
- Sourcing researchers to do a study into the prevalence of Polio in Australia
- Launching Polio Australia's quarterly Newsletter, [Polio Oz News](#)
- Keeping up to date with international developments in the management of the Late Effects of Polio by attending [European Post Polio Conference](#)

Polio Australia's Committee of Management is made up of two

representatives from each state-based Polio Network and these Networks are our only 'members'. As most of the state Polio Networks are run by volunteer polio survivors who also require funding to provide services to their members, Polio Australia only receives a small Membership Fee from each of the six Networks.

Polio Australia has a three year grant from The Balnaves Foundation which funds the National Program Manager's salary. Polio Australia applies to numerous philanthropic organisations for each individual planned 'project'. This does not include 'operational' funding, so we are very thankful to Jill Pickering whose donation funds the office rental.

With only one paid staff member, and most other 'members' being polio survivors and/or responsible for their own Networks, Polio Australia is seeking your help to meet its ongoing financial needs.

We stress that it is vital to continue to support your own local Polio Network or Group as they provide an important service to the community.

However, if you would also like to support the work of Polio Australia, we would welcome any additional donations – no matter how big or small – to help build

our reserves to pay for operational expenses such as staff, promotional material, travel reimbursement, and program costs.

Donations can be made in the following ways:

- On Polio Australia's **website** through [PayPal](#)
- **Internet** banking/direct credit to Polio Australia Inc account: Westpac (Parramatta Branch, NSW) – BSB 032-078 / Account 555766 (please ensure that you quote your Family Name on your internet banking transaction and email Polio Australia the details)
- **Deposit** the money at a local Westpac branch into Polio Australia Inc account: Westpac (Parramatta Branch, NSW) – BSB 032-078 / Account 555766
- **Cheque** made out to Polio Australia Incorporated, PO Box 500, Kew East, Vic, 3102

Alternatively, you might know of an independent philanthropist who is looking for a good 'investment'. If you have any solid leads in this area, please contact Mary-ann Liethof, National Program Manager, on 03 9016 7678 or office@polioaustralia.org.au.

Polio Australia is a charity with DGR status so all donations over \$2.00 are tax deductible.

Update on Audrey Clarke's City2Surf Run



Audrey (right) with Ross (left) and Brian Wilson (centre), Convenor of the ACT Post Polio Support Group

Canberra based Audrey Clarke completed her City2Surf in 95 minutes on Sunday, 14 August 2011, raising more than \$400.00 for Polio Australia.

Prior to moving to Canberra two and a half years ago, Audrey had intended to run the women's mini marathon in Ireland to raise funds for the Irish Polio Support Group, which her mother, Olive Haslam, belongs to. Olive, who still lives in Ireland, contracted polio in 1953 when she was two years old and is now experiencing its late effects.

To get a better understanding of the polio community in Australia, Audrey and her husband, Ross, visited Brian Wilson and the ACT Post Polio Support Group the week before her run (*photo left*).

Audrey said she intends running the half marathon next March/April in Canberra (22km) if it goes ahead. Otherwise, she'll run the half marathon in Sydney. Once again, Audrey will be donating her sponsorship money to Polio Australia.

Thanks Audrey—every bit helps!

Vaccination: A victim of its own success

by Dr James Best

21 September 2011

Source: [Sydney Morning Herald](#)

Dr James Best explains why opting out of vaccination is not an option.

In a piece in "Life&Style" last week, "[Vaccination's vexed link to autism](#)", freelance journalist Marj Lefroy once again resurrects the 'controversy' regarding autism and vaccines.

To me, a busy GP with a big paediatric practice in the inner-west of Sydney, servicing a largely middle-class and well-educated patient base, there doesn't seem to be much controversy at all. The vast majority of my patients are happy to follow the recommended immunisation schedule; perhaps one in 100 isn't.

I'm also better qualified to write on this subject than most doctors because I have a 10-year-old son with autism.

At first glance Ms Lefroy's piece appears measured and balanced. But that's only at first glance. It's more about what she doesn't say than what she does that's the problem. First she says that we still don't know 'what exactly causes autism'. This is true only to a point. Autism is strongly genetic in origin; a recent study found that if you have one child with an autism spectrum disorder (ASD) you have an 18 per cent chance of having another, a much higher figure than previously thought. Researchers have also identified a number of risk factors: older mothers, older fathers, birth complications, low-birth weight babies and twins, all factors that point to ASDs developing in utero, even though symptoms may not become apparent until many months after birth.

And yes, scientists are looking closely at environmental contributors such as pesticides and infections in pregnant mothers. Vaccines are only one

environmental factor under investigation but are by far the best studied. When, several years ago, concerns were first raised that childhood vaccinations may be linked to autism the mainstream medical community took these worries seriously and conducted study after study around the world: these were consistent in their outcomes: no link, no link, no link, no link.

Ms Lefroy then brings up the case of a young girl with a rare genetic mitochondrial disorder who received a substantial payout under the US National Vaccine Injury Compensation Program when she developed an encephalopathy with 'features of autism' - not 'autism' as Ms Lefroy claims - after receiving several vaccines. (Encephalopathy is an extremely rare but recognised side effect of some vaccines. That's why the US government didn't contest the case.)

What she doesn't mention was that this case was originally part of the much larger Omnibus Autism trial, a class action representing almost 5000—yes 5000—cases brought by families who claimed their child had developed autism from vaccines. And what happened to the other 5000 or so cases? After hearing months of testimony and reviewing mountains of evidence on the test claims, the independent Special Masters of the Vaccine Court dismissed them; in fact they were scathing in their judgements of the lawyers who pursued the action based on such flimsy evidence. 'Not even close', was one judgement.

Thirdly Ms Lefroy quotes an [interview with Dr David Amaral](#), from the University of California, in which he comments: "there is a small subset of children who *may be* (emphasis my own) particularly vulnerable to vaccines if the child had a precondition like a mitochondrial defect...."

What she omits to mention is what Dr Amaral says directly before this: "*So I think it's pretty clear that, in general, vaccines are not the culprit. There has been enough*

epidemiological evidence showing that if you look at children that receive the standard childhood vaccines that, if anything, those children are at slightly less risk of having autism than children that aren't immunised."

Whatever your feelings about this exchange, Dr Amaral - one autism researcher amongst many thousands - is simply expressing an opinion; his conclusions are not based on actual research. It remains a theoretical risk in a very rare number of cases. Do we need to continue our investigations to find more answers? Absolutely; as the parent of a child with autism I want to know as much as possible.

Finally, Ms Lefroy seems to me to be a little unclear how vaccines actually work. She suggests: "*We can change the way they're administered (using drops instead of injections, so the virus can be broken down by the immune system's natural defence mechanisms before it gets into the bloodstream, instead of being propelled straight into it at full strength).*"

Oral vaccines are not safer than injectable vaccines, and are sometimes even stronger, as they are live (but weakened) vaccines rather than killed. They are not broken down before going into the bloodstream; the immune system simply reacts to them, like it should. I could go on, but I won't.

When deciding whether to vaccinate their children or not parents have to weigh up the risks (of side effects) and benefits (prevention of disease). Unfortunately, vaccines have become a victim of their own success and younger parents are unable to remember the days when infectious diseases such as polio terrorised communities. That's tipped the balance, leading some parents to worry (sometimes excessively) about side effects.

If one parent, or two or even three elects not to vaccinate their kids that's fine; their children are still protected because there's not

Vaccination: A victim of its own success (cont'd from P20)

enough unvaccinated individuals in their community for an infectious disease to take hold. If, however, vaccination rates drop below a certain level, as has happened in some areas, such as after the autism scares, then it becomes a real problem and illnesses we thought we'd eradicated can make a comeback.

That's happening right now. Over the last 12-18 months or so, I have personally diagnosed and confirmed by throat swabs 30 or so cases of whooping cough, mostly in children. This is not unusual or exceptional; GPs all around Australia are doing the same. In the last few years, we have been in a large upswing of whooping cough case diagnoses, numbering in the tens of thousands. In fact, in other areas, particularly the eastern suburbs of Sydney and the far north coast of NSW, where immunisation rates have dropped to alarming levels due to vaccination scares, the rates

of diagnosis of whooping cough are far higher than where I work. As of a few years ago, I had never seen a case of whooping cough (despite having working as a doctor in Australia for twenty-one years).

Also, just last week, I received yet another notification from the Public Health Unit of measles cases being diagnosed in the south west areas of Sydney and the Southern Highlands. This is real, this is dangerous, and yes, this is scary.

Why? Whooping cough in an infant is terrifying, a medical emergency. They can damage their lungs permanently, get brain damage from lack of oxygen to their brain, and they can die. In all, five Australian babies have died from whooping cough since 2008. Imagine being the parent of one of these children.

As for measles, well, don't get me started. Measles is just plain bad. One in 20 children who get measles [also] get pneumonia as a

complication. For every 1000 cases of measles, one to two children will die. Yes, die.

So, where do we go from here? Do you vaccinate your child? Well, of course, the choice is yours. If it were me, (and remember, if I had another child he or she would have a higher chance of having autism) it would be a no-brainer - vaccinate away.

In her article Ms Lefroy claims to be concerned about parental anxiety surrounding vaccines. Funny then that she then proceeds to create anxiety based on a theoretical risk that they may contribute to autism in a tiny minority of cases, whilst ignoring the all too real risk of discouraging vaccinations - the resurgence of potentially disabling, life-threatening and preventable diseases.

Dr James Best is a GP and the father of three boys, one of whom has autism. All three of his sons have been completely vaccinated. 🌟

MP's urged to join world push to wipe out polio



by Judith Ireland

20 September 2011

Source: [Canberra Times](#)

Australian of the Year 2011 Simon McKeon has called on Australia's parliamentarians to help put an end to polio.

At Parliament House last night, the investment banker and philanthropist announced his support for The End of Polio campaign, designed to raise US\$590 million needed to eradicate the disease through immunisation.

"We defeated smallpox 34 years

ago, why haven't we done a repeat exercise with something as obvious as polio?" Mr McKeon said.

Since the introduction of vaccines in the 1950s and 1960s, the highly infectious disease, which can cause permanent paralysis, has almost been wiped out. The number of polio cases worldwide fell from 350,000 a year in 1988 to 1349 in 2010. But polio is still endemic in Commonwealth countries Nigeria, India and Pakistan as well as Afghanistan.

An initiative of advocacy group, The Global Poverty Project, the polio campaign asks the Australian Government to contribute \$50 million to the Global Polio Eradication Initiative, a partnership between governments and organisations such as Rotary International, the World Health Organisation and the United Nations Children's Fund.

[The End of Polio campaign](#) also

seeks to put polio on the agenda at the Commonwealth Heads of Government Meeting in Perth next month.

Mr McKeon, who is a director of The Global Poverty Project, said the global community should have stamped out polio years ago.

"We have an opportunity now for literally a few hundred million dollars to assign it to the history books," he said.

"I would go so far as to say, the fact that we haven't obliterated it, is actually a bit of a blight on us."

The current Australian of the Year said that despite being a global problem, polio was still an Australian concern.

Last month, Canberra MP Andrew Leigh moved a motion in Parliament, calling upon the Government to support efforts to deliver a polio-free world. 🌟

Polio Strain Spreads to China from Pakistan



Source: [Global Polio Eradication Initiative](#)

The Ministry of Health, China, has informed WHO that wild poliovirus type 1 (WPV1) has been isolated from four young children, aged between four months and two years, with onset of paralysis between 3 and 27 July 2011. All four cases are from Hotan Prefecture, Xinjiang Uygur Autonomous Region, China. Genetic sequencing of the isolated viruses indicates they are genetically-related to viruses currently circulating in Pakistan. The last WPV case in China was reported in 1999, due to an importation from India. The last indigenous polio case occurred in China in 1994.

A national team of clinicians, laboratory experts, epidemiologists and public health experts has been dispatched to the affected region, to assist in the investigation and planning of response activities, and this team will be joined by international support as required. National, Xinjiang Uygur Autonomous Region and local public health authorities are currently conducting an epidemiological investigation, including collection of stool specimens from contacts and evaluation of vaccine coverage.

The Ministry of Health plans to conduct an initial response vaccination campaign in early September, targeting 3.8 million children aged under 15 years in the key affected outbreak area, and children aged under 5 years in other areas of Xinjiang. 🇨🇳

Polio this week: Wednesday 13 September 2011

Total cases	Year-to-date 2011			Year-to-date 2010			Total in 2010*	
Globally	380			648			1349	
• in endemic countries:	130			103			232	
• in non-endemic countries:	250			545			1117	

Countries	Year-to-date 2011			Year-to-date 2010			Total in 2010*	Date of most recent case
	WPV1	WPV3	Total	WPV1	WPV3	Total		
Pakistan	83	1	84	30	18	48	144	26-Aug-11
Afghanistan	19		19	6	8	14	25	15-Aug-11
Nigeria	19	7	26	3	3	6	21	20-Jul-11
India	1		1	13	22	35	42	13-Jan-11
Chad	109	3	112		14	14	26	31-Jul-11
DRCongo	77		77	7		7	100	30-Jul-11
Angola	4		4	21		21	33	27-Mar-11
China	7		7					02-Aug-11
Kenya	1		1					30-Jul-11
Guinea		2	2					27-Jul-11
Côte d'Ivoire		34	34					24-Jul-11
Niger	1	1	2		2	2	2	09-Jul-11
Mali		7	7	3		3	4	23-Jun-11
Burkina Faso		2	2					15-Jun-11
Congo	1		1				441	22-Jan-11
Gabon	1		1					15-Jan-11
Uganda							4	15-Nov-10
Russian Federation				12		12	14	25-Sep-10
Liberia				1		1	2	08-Sep-10
Nepal				5		5	6	30-Aug-10
Kazakhstan							1	12-Aug-10
Tajikistan				456		456	457	04-Jul-10
Turkmenistan							3	28-Jun-10
Senegal				18		18	18	30-Apr-10
Mauritania				5		5	5	28-Apr-10
Sierra Leone				1		1	1	28-Feb-10
Total	323	57	380	581	67	648	1349	
Total in endemic countries	122	8	130	52	51	103	232	
Total outbreak	201	49	250	529	16	545	1117	

Data in WHO as of 14 Sep 2010 for 2010 data and 13 Sep 2011 for 2011 data. *The 2010 total for Congo includes cases with inadequate specimens that have been exceptionally classified as confirmed polio based on their association with the WPV1 outbreak.

Making the World Polio Free

Source: [Radio Australia](#)

25 August 2011

Listen and download: [MP3](#)



The move to eradicate polio is almost reaching its completion as the world moves to tackle the final one per cent. But efforts to make the world polio free are being compromised by lack of funds and restricted access to remote villages.

Polio is caused by a virus and often does not produce symptoms at all. As there is no cure to this highly contagious disease, the global strategy to eradicate polio is based on prevention by immunizing every child until transmission stops. Polio remains endemic in Afghanistan, India, Nigeria and Pakistan.

Both resident doctor Ron McCoy and the Manager of the End of Polio campaign Michael Sheldrick agree that the world is very close on eradicating polio. However, access to some of the remote villages in countries where polio remains an endemic disease and lack of funds are some of the barriers preventing the world from being polio free.

Presenter: *Megan Flamer*

Speaker: *Dr Ronald McCoy from the Royal Australian College of General Practitioners and Michael Sheldrick, Manager of the End of Polio campaign with the Global Poverty Project.* 🌐

Sanofi Pasteur Donates Vaccine to WHO

Source: [PRNewswire](#)

20 September 2011

Sanofi Pasteur, the vaccines division of Sanofi (EURONEXT: SAN and NYSE: SNY), announced today it is donating to the World Health Organization (WHO) a vaccine strain used for polio eradication. The biological material given by Sanofi Pasteur is the original viral seed used to produce large quantities of oral polio vaccines (OPV) against type 3 poliovirus. With this donation from Sanofi Pasteur, WHO will be in full control of the storage of the vaccine strain and its distribution to vaccine producers worldwide.

"Sanofi Pasteur is a leading contributor to the fight against polio and committed supporter of the Global Polio Eradication Initiative," said Olivier Charmeil, President and CEO of Sanofi Pasteur. "We have provided polio type 3 viral seeds free of charge to polio vaccine manufacturers worldwide for the last 30 years. This donation is a logical next step to our 30-year unconditional support to OPV producers and a demonstration of our continued commitment to public health."

Since 1988, the Global Polio Eradication Initiative, spearheaded by WHO, Rotary International, the

US Centers for Disease Control and Prevention (CDC) and UNICEF, has achieved a 99% reduction of the number of polio cases worldwide. Polio is caused by three strains of poliovirus, types 1, 2 and 3. Wild poliovirus type 2 has already been eliminated, and it is hoped that polio types 1 and 3 will be eradicated within a few years, definitively wiping polio from the surface of the earth.

OPV is instrumental for the roll-out of nationwide immunization days. The OPV type 3 vaccine strain was officially recommended in 1990 by WHO as the standard for producing oral polio vaccine (OPV) type 3. 🌐

Vadodara to Host National Seminar on Post Polio Syndrome

Source: [Times of India](#)

VADODARA: The city will host a national seminar on post-polio syndrome (PPS) in October this year. The Indian Medical Association (IMA) has also decided to support the movement initiated in the city [regarding] the syndrome.

The issue of PPS being a major problem faced by polio-affected persons was raised for the first time last year at a meet in the city. It

was at this stage that Vadodara MP Balkrishna Shukla had proposed to put a bill regarding PPS in the Lok Sabha. The Pulse Polio Syndrome (Education, Training and Awareness) Bill was introduced in February this year and has been categorised as a category 'A' private member bill that gets priority over other private member bills.

Persons suffering from polio face health problems like joint and muscle pain, fatigue, weakness,

breathing problems and trouble in swallowing after 25 to 30 years of contracting polio. However, there is little awareness on this issue.

Shukla on Saturday said IMA had agreed to take up the issue of PPS at a seminar in Vadodara on October 24, the World Polio Day. Shukla said that this will also mark the beginning of a movement against PPS across the country. "The IMA president Dr Vinay Agrawal and honorary secretary general Dr D R Rai have agreed to participate in the event," he said. 🌐

Australia's GPs are the Front Line of Primary Care

Source: [Minister for Health and Ageing](#)

19 September 2011

The following article by Minister for Health and Ageing Nicola Roxon was published today in the *Medical Observer*.

Every day those in medical centres across Australia experience the pressures associated with the rising levels of chronic disease, the greater complexity of patient presentations and the demands of an ageing population.

With around 75% of the population reporting that they have one or more current long-term medical conditions, doctors are seeing patients walking into their GP clinics with increasing frequency.

Our ageing population is compounding this situation, with nearly all people aged 65 years or older having at least one long-term condition and more than 80% of people in this age group having three or more long-term conditions. Often our GPs can find it difficult to link to the range and mix of local hospital, specialist and allied health services that patients need to be connected with.

We need to enhance primary care, support those GPs on the front line and better connect services for the consumer.

These are the aims of Medicare Locals and why they play such an important part in a reformed health system.

Medicare Locals are a more inclusive and responsive primary care model - they are developing local health solutions to local needs.

Medicare Locals will also work with a wide range of health professionals to better integrate and coordinate local services to improve care for the patient and support clinicians who provide that care.

Already the Metro North Brisbane Medicare Local is working with local GPs to deliver eHealth records across their region to assist elderly chronic disease patients.

The Western Sydney Medicare Local assessed local population health needs and service gaps and is focusing its early efforts on Closing the Gap for Indigenous Australians and tackling chronic disease through healthy lifestyle programs.

The Barwon Medicare Local in south-west Victoria has responded to the needs of local GPs and developed an electronic navigation portal that helps GPs identify local mental health services in order to provide patients with referrals that suit their time, cost and geographical needs.

There is no one-size-fits-all for Medicare Locals. What works in

Western Sydney won't necessarily work in Brisbane, which is why the locally run organisations are looking at the health needs of their community and targeting services to meet these needs.

The Government knows that nationally, communities need better access to after-hours GP care, chronic disease prevention and management programs and mental health initiatives, and these areas will be early priorities for many Medicare Locals.

Medicare Locals will provide new opportunities to improve primary care - new opportunities that GPs are perfectly placed to take.

All doctors want to keep Australians healthy, out of hospital and able to access the care they need close to home and when they need it.

Their role at the heart of our health system, gives them a unique insight into how to improve and better coordinate services.

Medicare Locals are there to support the front line of primary care and help hard working health professionals better meet the health needs of their community.

For more information, contact the Minister's Office on (02) 6277 7220



Disability Care and Support

Productivity Commission's final report into disability care and support

10 August 2011

Source: [Prime Minister, Minister for Community Services, Assistant Treasurer, Parliamentary Secretary for Disabilities and Carers](#)

The Gillard Labor Government today announced that it will start work immediately with states and territories on measures that will build the foundations for a National

Disability Insurance Scheme, following the release of the Productivity Commission's final report into the matter.

The Government asked the Productivity Commission to examine reform of disability support services because we believe that the system we have today is not delivering the kind of care and support Australians expect for people with disability.

The main recommendations of the Productivity Commission are:

- A National Disability Insurance

Scheme should be created to provide all Australians with insurance for the costs of support if they or a family member acquire a disability. The scheme will provide individually tailored care and support to around 410 000 people with significant disabilities.

- A National Injury Insurance Scheme should be created to provide no fault insurance for anyone who suffers a catastrophic injury.

The Productivity Commission's

Disability Care and Support (cont'd from P24)

report finds that it would take at least seven years to transform disability services.

The Australian Government supports the Productivity Commission's vision for a system that provides individuals with the support they need over the course of their lifetime, and wants reform of disability services that is financially sustainable.

The Productivity Commission outlines the creation of these schemes would ensure that every Australian can have confidence that they will receive the care and support they need if they acquire or are born with a disability.

However, the Productivity Commission makes clear that important work needs to be done before further progress can be made – and we want to get that under way.

While we have a lot of work to do before the Government could determine the design of a scheme, we believe it is important that work begins now to lay the foundations for this reform.

In line with the Productivity Commission's recommendations, the Government, with the States and Territories, will start work immediately on building the foundations for reform. We will:

- Deliver an immediate, additional \$10 million, consistent with the PC recommendations, to support this technical policy work;
- Move to establish a COAG Select Council of Ministers from the Commonwealth, States and Territories to lead reform in this area at COAG next month;
- Take steps to establish an Advisory Group to the Select Council, led by Dr Jeff Harmer, to provide expert advice on delivering the foundations for reform and preparation for launch.

The current system is not delivering the kind of care and support Australians expect for people with a disability.

Care and support should be based on people's needs, not a lottery of what kind of disability they have, how they acquired it or where they live.

That's why the Government put disability reform on the agenda and we thank the Productivity Commission for their work.

Future reform of disability services will require investment from all levels of Government.

Further policy work

The Productivity Commission recommended that foundation reforms were a necessary precursor to the establishment of a functional and efficient national scheme. Work is required to:

- develop common assessment tools to determine eligibility for support
- develop service and quality standards so that people with disability can expect high quality support irrespective of what disability they have or how they acquired it
- develop a national pricing structure
- build the capacity of the disability sector
- build workforce capacity
- Work on these foundation reforms will recognise the roles and responsibilities of governments as outlined in the National Disability Agreement and recently reaffirmed in the National Health Reform Agreement.

Select Council

The Prime Minister will seek to establish a Select Council on Disability Reform at the next meeting of the Council of Australian Governments. This would bring together Commonwealth and State Treasurers and Disability Ministers to do the work needed to lay the foundations for change.

The Select Council would be chaired by the Treasurer and Minister Macklin, and would be supported by an Advisory Group of experts and

leaders on disability reform.

In response to the Productivity Commission's recommendations for the states and territories to harmonise their approach to catastrophic injury, the Government will also convene a working group led by the Assistant Treasurer to work with State and Territory Governments, lawyers and other stakeholders to progress this important complementary reform.

Advisory Group

The Advisory Group will be led by Dr Jeff Harmer AO, and the Commonwealth will nominate highly regarded national disability advocates Mr Bruce Bonyhady AM and Dr Rhonda Galbally AO to this Advisory Group.

Suggestions for additional nominees to this group have also been sought from the states and territories.

These reforms will be delivered in a way that is consistent with the Government's fiscal strategy.

For a copy of the Productivity Commission report visit <http://www.pc.gov.au/projects/inquiry/disability-support/report/>

