NETWORK NEWS

Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

Welcome to the first edition of *Network News* for 2016. This issue is the first that will be going out by email to those members who have elected to receive it electronically. To date, just under 40 members have chosen this option. If you are currently receiving a paper copy of the newsletter and would prefer to instead receive it by email in future, please just let the Office know.

On pages 2 and 3 you will find full details of our upcoming mid-year Seminar, to be held at the Northcott Society in Parramatta on Wednesday, 18th May. The topic for the day is "*Pain Management*". With three excellent speakers presenting on various aspects of the subject, this is a Seminar you won't want to miss. Note that this year the mid-year Seminar is being held two months earlier than usual, in order to avoid the colder weather – we hope this will encourage more members to attend. It takes many hours of work to organise a Seminar and we encourage you to make an effort to support not only the Seminar but the presenters who freely give of their time to speak to us. Of course, Seminars are also a great opportunity to meet up with other members and socialise in the breaks and over lunch. Please be sure to return the enclosed Registration Form by Friday, 13th May so sufficient catering can be arranged.

In less than six months, 20th to 22nd September this year will see the *Australasia-Pacific Post-Polio Conference "Polio – Life Stage Matters"* staged in Sydney. In organising this Conference, Polio Australia has done its utmost to keep costs for polio survivors, their families, carers and friends to an absolute minimum. With time ticking down to this watershed event, and many already registered, it is time to book your place. Full Conference details can be found on the dedicated website <www.postpolioconference.org.au>, and online registration is quick and easy. If you can't register online, just ring the Conference planner, Interpoint Events, on 02 8586 6103 or 1300 789 845.

As Mary-ann Liethof, Polio Australia's National Program Manager, writes: "This unique Conference aims to provide a broad range of health professionals with gold standard diagnosis, treatment, and management strategies to provide the best care possible for post-polio patients. Polio survivors, and their family/carers/friends, will also gain unprecedented access to information to assist them with self-management techniques. In short, there is something for everyone! DON'T MISS OUT on this not-likely-to-be-repeated education opportunity. Register now!"

To whet your appetite as to what the Conference has to offer, here are a few quick facts. There are 26 invited speakers (14 Australian, 12 international), and more than 60 abstracts have been received for oral presentations across the three days. There will also be poster presentations. The full program and abstract summaries can be downloaded from the Conference website, or you can contact the Polio NSW Office for assistance if you don't have internet access. In the *Polio Oz News* accompanying this edition of *Network News*, you can also have a sneak preview of just four of the Conference presentations. We look forward to seeing many Polio NSW members in September.

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One-Day Seminar - Managing Pain

Date: Wednesday, 18th May 2016

Time: 9:30 am – 3:00 pm

Venue: The Northcott Building, Ground Floor, 1 Fennell Street, Parramatta

A special arrangement has been made to enable members and friends attending the Seminar to park in the Parramatta Leagues Club car park, thanks to the generosity of the Club management. Simply tell the security person at the car park entrance in Grose Street that you are attending the Polio NSW Seminar in the Northcott Building, and please park in the right-hand back corner of the car park. You can then enter the Northcott Building via the gate into its adjacent playground.

Refreshments: Morning tea and a light lunch will be provided

Cost: \$10 per person RSVP by Friday 13th May 2016

Please return the **enclosed Registration Form** with your payment to the Polio NSW Office by 13th May. You can pay when you arrive at the Seminar, however, if you elect to do this, you MUST still contact the Office [*email* office@polionsw.org.au or *Phone* 02 9890 0946] by Friday 13th May to confirm your attendance so sufficient catering can be arranged.

Program:	9:30	Registration
	10:00	Morning Tea
	10:20	Welcome by Polio NSW President, Gillian Thomas
	10:30	Dr Toby Newton-John , Senior Clinical Psychologist, North Shore Private Hospital Pain Centre Self-management of Persistent Pain: 5 Useful Strategies
	11:30	Break
	11:45	Amal Helou , Nurse Practitioner, Royal Prince Alfred Hospital Pain Management Centre <i>Pain Management</i>
	12:45	Lunch
	1:45	Melissa McConaghy, Neurological Physiotherapist, Managing Director of Advance Rehab Centre, Artarmon Care of the Shoulder
	3:00	Close

All are welcome – we look forward to catching up with everyone on 18th May 2016

Dr Toby Newton-John: Dr Newton-John is a Clinical Psychologist and Senior Lecturer in the Graduate School of Health at UTS (University of Technology Sydney). He completed undergraduate psychology and postgraduate clinical psychology training at the University of Sydney before moving to the UK to undertake a PhD in pain psychology at the University of London. Toby has worked in a range of clinical health settings in Australia and the UK. He established a large multidisciplinary pain management program in Newcastle NSW and moved into an academic position in 2013. He continues to practice as a clinical psychologist on a part-time basis at Northern Private Pain Centre, North Shore Private Hospital. Toby's clinical as well as research interest has been in the social aspects of chronic illness, particularly the reciprocal influences of the primary relationship on illness adjustment. He has ongoing research collaborations with Relationships Australia and overseas universities.

Dr Newton-John has expressed an interest in collecting information from our members for his research.

Amal Helou: Amal has over 30 years' experience in pain management, and is employed as a nurse practitioner in the Pain Management Centre at Royal Prince Alfred Hospital. Amal has particular interest in patient and family education and has actively worked and advocated for pain management in the older person in hospital and community settings. She is also interested in exploring patient narrative as a therapeutic intervention and the impact persistent pain has on the whole individual. Amal is on the ACI (Agency of Clinical Innovation) pain network steering committee which helps to support new pain services and develop pain research in NSW.

Melissa McConaghy: Melissa McConaghy has extensive experience in neurological rehabilitation and holds a Master of Health Science (Neurological Physiotherapy) and Graduate Certificate in Public Health. Melissa is also an APA Titled Neurological Physiotherapist and Chair of the APA NSW Neurology Group Chapter. Melissa established Advance Rehab Centre in 2005 after recognising the need for a rehabilitation service providing expert and professional neurological therapy in Sydney. During her career, Melissa has worked in a variety of rehabilitation settings both here and overseas including Wales, India, Thailand and England. She is a senior clinician and has been supervising and teaching junior staff for over eight years. Advance Rehab Centre now comprises a growing team of over 15 allied health members offering both a home-based service and purpose-built rehabilitation centre in St Leonards, Sydney. As the lead educator for Polio Australia's pilot *LEOP Clinical Practice Workshops* series (*see page 15*) Melissa is currently delivering training on management of the late effects of polio to a wide range of health professionals.



Interviews - ABC Radio National

On Saturday 13th February 2016 at 1 pm, Gillian Thomas (*President of Polio NSW and Vice-President of Polio Australia*), John Tierney (*President of Polio Australia*) and Billie Thow (*polio survivor from Tasmania and Board Member of Polio Australia*), were interviewed on ABC Radio National – *The Body Sphere* Program – about post-polio.

Also featured was Medical Historian, Kerry Highley, talking about her book "*Dancing in My Dreams: Confronting the Spectre of Polio*". Kerry will be giving the Closing Plenary at the Australasia-Pacific Post-Polio Conference being held in Sydney on 20-22 September 2016.

To listen to the interviews, go to this page and click on Listen Now:

www.abc.net.au/radionational/programs/bodysphere/polio-then-and-now/7143534

REMINDER: LEOP Assessment Clinle - Mt Wilga

The *Late Effects of Polio Assessment Clinic* is a one-day clinic, held fortnightly, and includes medical, physiotherapy and occupational therapy assessments under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie.

How do I make an appointment to attend the Clinic?

Obtain a referral from your GP or other specialist who can fax it to Dr Helen Mackie on **02 9847 5013**. Once it has been received, Dr Mackie's secretary will telephone you to make an appointment for assessment. Dr Mackie has recently advised that Clinic appointments are booked up to August 2016 and new appointments will not now be made until after the Australasia-Pacific Post-Polio Conference in September, 2016. In the meantime, you can still make contact, as names will be put on a waiting list. If you would like any more information, please contact Dr Mackie's office on **02 9847 5085**.

You will also be sent a medical questionnaire to be completed and forwarded to Dr Mackie **two weeks** prior to your appointment.

Return the questionnaire by email to <helenmackie@bigpond.com.au> or by mail to: LEoP Clinic, Mt Wilga Private Hospital, 66 Rosamond Street, Hornsby NSW 2077.

Where does the Assessment Clinic take place?

The Assessment Clinic is at Mt Wilga Private Hospital, a specialist dedicated rehabilitation hospital and day-therapy centre. The address is:

66 Rosamond Street Hornsby NSW 2077

www.mtwilgaprivate.com.au

** Read the AGM Seminar Report on Dr Mackie's Clinic presentation (pages 6-9) **

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ORTHOTIC AND MEDICAL GRADE FOOTWEAR

by Susan Ellis

Many of our members will be accustomed to wearing a calliper (or brace) that perhaps inserts into ferrules in their shoe or boot heel. Callipers are now more commonly known as orthoses, AFOs (ankle/foot orthoses) or KAFOs (knee/ankle/foot orthoses). These usually have a moulded section under the foot that goes into the shoe. These orthoses require footwear that can accommodate this extended foot section, that is, a shoe that is deeper and wider than we would normally wear.

I have spoken to a number of members recently who have had difficulty finding suitable footwear, some of whom have their shoes custom-made as I once did. I have found a solution for my shoe/orthosis issues at Barefoot Freedom who provide medical-grade shoes that are double depth and double width to accommodate my orthosis. The brand of shoe I order is Drew. They also provide shoes for very narrow feet and sizing from 5 -13.

Some of our members may remember Barefoot Freedom attending our 2014 Retreat to display their footwear. They are registered as a provider with all major medical funds as well as being an approved provider for the Department of Veterans' Affairs (DVA).

Barefoot Freedom also provide a service where you can purchase split sizes, for example, left foot size 4 and right foot size 7, eliminating having to purchase two pairs of shoes (a small additional fee applies, however). Alterations can also be made, for example, a build-up to one shoe, elongating a strap. They look after many different foot problems.

Barefoot Freedom are at: St Leonards, Pymble, Enfield and Newcastle. Ph: 02 9438 5554 Email: <enquiries@barefootfreedom.com.au> Web: <www.barefootfreedom.com.au>

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AGM Seminar Report

by Susan Ellis

Saturday, 5th December 2015

Gillian Thomas, Polio NSW President, introduced the Seminar and offered some insight into how the Clinic came to fruition as well as other interesting developments to take place in 2016.

Today we are very pleased to welcome Dr Helen Mackie, Rehabilitation Physician, and Nadege van Drempt, Occupational Therapist, both from Mt Wilga Private Hospital in Hornsby, to tell us all about the multi-disciplinary *Late Effects of Polio Assessment Clinic* which has been established at Mt Wilga.

Before I hand over to Merle to introduce our first speaker, Dr Mackie, I thought a little background might be in order.

Those of you who have been members for a long time will remember that we had a Polio Clinic at Prince Henry in the 1990s which was established by Professor Richard Jones and staffed by rehabilitation specialist Dr Jill Middleton and, later, her colleague Dr Pesi Katrak. After Jill retired, and Prince Henry closed, with its services relocating to the Prince of Wales Hospital, Dr Katrak still saw some polio patients but the concept of a Clinic was really lost. Although this Clinic was not exactly multi-disciplinary (for example, it did not include a physio, occupational therapist, orthotist etc as part of the rehab specialists' team) at least it was somewhere we could go for an assessment of our polio-related difficulties and get relevant referrals, and so its loss was felt keenly. The Management Committee has been lobbying hard for a similar service ever since.

A number of years ago, Advance Rehab Centre (ARC) at St Leonards started a Polio Mobility Clinic and I know many of our members have taken advantage of it. This Clinic includes consultation by a physiotherapist, neuromuscular orthotist, occupational therapist and speech pathologist. ARC also do home visits. This Clinic has gone some way to filling the gap, but we needed more for members.

In 2014, Committee members Nola Buck and Merle Thompson started working with Dr Mackie with a view to having a multi-disciplinary *Late Effects of Polio Assessment Clinic* established. With Dr Mackie's support and Nola's and Merle's dedicated efforts we have now seen the Clinic come to fruition.

Just before Merle introduces Dr Mackie to you, I wanted to quickly bring you up to date with some related work that Polio Australia is doing, in conjunction with Rotary District 9685. This district stretches from the Blue Mountains to the sea, north of Sydney Harbour, across the Hawkesbury River and north to Toukley on the Central Coast.

Over the next few months, a series of ten clinical practice workshops are being delivered to allied health professionals wishing to learn more about management of the late effects of polio. The experienced therapists at ARC are providing the training, and we are hopeful that across the series we will improve knowledge about management of the late effects for more than 150 allied and other health practitioners such as physiotherapists, occupational therapists, orthotists, exercise physiologists, nurses, podiatrists, speech pathologists, dietitians, social workers, case managers, and anyone else who is interested in knowing more about the post-polio body.

This is a very exciting development and a successful pilot will give us runs on the board to get Rotary's ongoing support to replicate the workshop series across NSW, and the rest of Australia, over time.

So with the Mt Wilga Clinic, the Clinical Practice Workshops, and the Australasia-Pacific Conference next September, these are exciting times.

The New Assessment Clinic for Polio Survivors at Mt Wilga

Dr Helen Mackie is a Consultant in Rehabilitation Medicine at Mt Wilga Private Hospital. She is the Director of the Late Effects of Polio (LEoP) Assessment Clinic, newly established in 2015, as well as Director of the Lymphoedema Service at Mt Wilga Private Hospital which was established in 1991. She is the current President of the Australasian Lymphology Association and is a member of the International Society of Lymphology.

One of the reasons Dr Mackie wanted to give her talk was to thank everyone for their support. It has been the wonderful advertising of the Clinic by Polio NSW that has really made it a success. Dr Mackie explained the Clinic's current status, some of the issues that have been found and subsequent changes made, and then looked forward to the future.

Dr Mackie met some of us at Polio NSW's 2014 Retreat and from there suggestions were made for a Clinic and she was keen to get involved. It was from various conversations, often with people who came as patients to see Dr Mackie at Mt Wilga for other problems, legs swelling and so on, that led to a discussion with Polio NSW about a Clinic. With Merle Thompson's recommendations, Mt Wilga contacted Victorian rehabilitation specialist Dr Stephen de Graaff and Polio Services Victoria to see what they were doing, as well as NSW rehabilitation specialist Dr Jill Middleton, and neurophysiotherapist Anne Buchan from South Australia.

Talks ensued with Mt Wilga and costs were discussed and it was eventually decided that a monthly Clinic would be set up with three people being assessed at each Clinic with the out-of-pocket expenses being \$330 for the actual assessment. This was made up of Dr Mackie's assessment (covered by Medicare), and physiotherapy and occupational therapy assessments, with some rebate available from a private health fund or a Chronic Care Plan.

Response came after the Clinic was advertised by Polio NSW and also by Mt Wilga's connections as well through local medical services etc. All arrangements are made through Dr Mackie's office – the direct line to her office staff is 02 9847 5085.

The Clinic started in April 2015 but was really getting going by June where it was found that all appointments were filled up for 2015 (a total of 15 people). It was realised that some fortnightly clinics had to be opened up which meant that by year's end they will have seen 26 people in total. The Clinic is now booked through to May 2016, with 6 people on the waiting list. By end of June 2016, 50 people will have been assessed. [*Ed: The Clinic is now booked up until August 2016 – see page 4 for more information.*]

Clients are required to obtain a referral from their GP or specialist (ask them if you are eligible for a Chronic Care Plan) and a patient questionnaire is sent out to the client to be completed and returned to the Clinic at least two weeks prior to the appointment. This questionnaire will also ask what your issues are, what your goals are, and what you expect from the Clinic.

The three-hour Clinic starts at 9:30 am with a one-hour per session rotational basis, seeing Dr Helen Mackie, Rehabilitation Specialist; Catriona Morehouse, Physiotherapist; and Nadege van Drempt, Occupational Therapist. Dr Mackie noted that the client at the beginning of the three hours can be a very different person by the end of the three hours, for example, their voice may start to wane.

Immediately after these sessions all three clinicians attend an LEoP Case Conference to discuss their thoughts and recommendations – this is really important in the assessment process. This process has been very constructive in getting an understanding of what polio survivors are going through. Some plans are made and each clinician makes individual

reports which are then compiled along with an executive summary. These reports are posted to the person attending, and to their doctor and other medical professionals that the person attending nominates, for example, their local physiotherapist.

The executive summary will include any recommendations as well as a full medical summary, history, examination details etc. The physiotherapy report will include muscle charting, balance and physical assessments, and recommendations. The occupational therapy report will include a functional assessment and recommendations. All up, it is a 7-to 8-page report. Follow up can be made with Mt Wilga after discussions with your GP or specialist.

Demographics

- > 21 clients to date (26 booked to end of 2015)
- > 7 males, 14 females between 53 and 88 years of age
- ➢ year at polio onset − 1935 to 1964
- > years with polio -50 to 80
- > age at polio onset 18 months to 11 years
- severity minimal to moderate (nil wheelchair)
- education nil attended special schooling
- highest level of schooling Year 10 = 5, Year 12 = 4, Tertiary = 11 (3 teachers, 2 accountants etc)

Ratings

- quality of life (out of 5) mean result was 4 (good)
- > quality of health (out of 5) mean result was 3.2 (neither satisfied nor dissatisfied)
- level of fatigue (out of 10) mean result was 7

Age Changes and LEoP

With ageing changes, skeletal muscle atrophy (thinning) appears to be inevitable. There is a gradual loss of the number of muscle fibres after the age of 50 and this continues so that by age 80 approximately 50% of the fibres are lost from the limb muscles.

The timing and magnitude of the loss of motor units is similar to that for muscle fibres and suggests that the mechanism responsible for this loss of fibres and the loss of whole motor units is the same.

The degree of muscle atrophy (thinning of the muscle) of the remaining fibres is largely dependent on the physical activity of the individual. The problem for people with polio is that there is a triple whammy – they have had polio, they have the natural ageing changes, and the activity level is difficult to maintain. Three issues that need to be addressed.

Fatigue

Fatigue is a very common problem; it is a sensation of weariness not relieved by rest. One in five GP consultations involves a component of fatigue as a symptom. Fatigue is more common in people over 60 and more common in women. Blood tests to investigate causes for fatigue, for example, anaemia, Vitamin D deficiency etc, will be abnormal in only 3% of tests. When looking at fatigue we need to look at a whole range of things – not only physical but psychological issues, as well as lifestyle and social causes of fatigue, and NOT just polio issues.

Also after speaking with polio clients, Dr Mackie's impression is that there are two different types of fatigue, generalised fatigue (tiredness) and muscle fatigue.

Pain

Dr Mackie found that pain hasn't been a major polio symptom as such. Sometimes people talked about pain in weak muscles, very rarely in muscles that are very weak or severely wasted, but rather in the muscles that are under strain – those that are weakened but are trying to do the job of a lot more muscles. This is really similar to the concept of fatigue in muscles, which can be quite painful.

Mostly people talk about pain in relationship to their joints and to areas where muscles are quite normal on the muscle chart but are doing a bigger job resulting in problems with tendons, muscles (rotator cuff tears) – all those sort of things are really a feature of pain.

Respiratory

A number of clients have had sleep studies and even if it was recommended, they very rarely use a CPAP machine.

Cold intolerance

This proved to be universal, and some also experienced humidity intolerance.

Swallowing

Swallowing issues haven't been a feature. However, there were issues with voice fatigue, some could no longer sing, and some by end of their interviews had difficulty 'getting a word out'. Some were recommended to have speech assessments by Mt Wilga's speech therapist.

Sleep

In the general community there is a lot of problem with sleep. Dr Mackie doesn't think it is any worse in the polio community. Restlessness and pain can cause poor sleep patterns.

Psychology

Psychology hasn't been assessed to any extent in the LEoP Clinic. There isn't enough time left for a psychology assessment and fatigue has been an issue after completing all the questionnaires for three assessments. Maybe the Clinic could do better in this area in the future. From Dr Mackie's point of view, there have been a variety of psychological issues being raised. There is certainly an issue about the anger of non-recognition of polio; a "pat on the back" and saying "there, there, polio is gone, don't worry about it". Also feelings of concern, worry, frustration or depression when having to deal with new changes after having coped all their lives and now finding it more difficult which is quite distressing.

What have they learnt?

In the first week of Clinic assessments they were doing a 6-minute walk test but after about a minute they realised it wasn't going to work for polio clients so they threw that one out of the assessment process!

What has been quite extraordinary to learn about has been the clients' childhood experiences – incredibly long hospitalisations, the isolation, and the stigma that was often felt. Although even more extraordinary seems to be that polio survivors were left behind in a sense through schooling, but everyone went back into the school system and got on with life and, although not leaving their experiences behind, they moved forward with resilience.

Clients have presented with a variety of symptoms, some quite minor problems, as well as as muscle wasting which can be put down to polio. It is here that muscle charting is essential for all muscles to detect the prevalence of muscle weakness. It is beneficial to bring along any previous muscle charts to the assessment to see if there has been any significant change over time.

What Issues Concern Clients?

The main issues that people have asked us to address are 'future- proofing' – the issues of balance and falls, concerns about their future post-retirement, planning for the future as we age and live longer. There has been a bit of resistance to aids and equipment, most thinking that they don't need to see an occupational therapist (OT), but after their OT assessment they had found it to be really helpful. It is quite a normal response to resist equipment and aids as they are an indication of change, but in many cases it is the one thing that we *can* do to alter our environment. There is an extraordinary range of things that can make life easier – why not take advantage of them?!

Outcomes

Of the 21 clients (some rural clients), 5 attended Mt Wilga following their assessment, 2 as inpatients and 3 as day patients. Information is made available as to what services are available in the client's local area and we try to link them with their current therapists.

Plans for the Future

A survey will be sent out to LEoP Clinic attendees to get feedback, to ask for ideas and suggestions, and to try and quantify the experience people have had and how useful the Clinic has been.

In April 2016, Mt Wilga will be one of the venues for the Polio Australia/Rotary Late Effects of Polio Clinical Practice Workshops. Mt Wilga has been in contact with the therapists who are presenting the workshops, Advanced Rehab Centre at Artarmon, and are very keen to network with them as they offer some services as well. They have had wonderful experience with polio clients.

Finally, Dr Mackie will give a more extensive presentation of the data from the LEoP Clinic at the Polio Australia International Conference in September 2016.



Nadege van Drempt is an Occupational Therapist (OT) who has a special interest in neurological rehabilitation. She has worked in a number of inpatient and outpatient settings in the Newcastle area, including a rural stroke team and with amputee clients. She has worked at Mt Wilga since 2004 working with patients with both neurological and orthopaedic conditions. She has completed her Masters in research. She is currently one of the OTs undertaking assessments at the LEoP Assessment Clinic.

REDUCING FALLS RISKS AND SIMPLIFYING DAILY ACTIVITIES

Occupational Therapy is about day to day activities and how to make them easier with some hints and tips to make life easier. An occupational therapist can come out to your home to assess your needs and offer ideas about equipment and solutions.

INTRODUCTION TO FALLS

Polio can cause muscle weakness, joint pain and fatigue which all can increase your falls risk. We know that people with polio fall more often than other adults over 55. Polio survivors report falling more, often in and around the home, and more often in the afternoon (about 60% of falls).

Predictors of falling identified for polio survivors:

- o problems maintaining balance,
- "knee buckling" in the weaker leg,
- o fear of falling.

Falls definition and causes

According to the World Health Organisation, a fall is "an event which results in a person coming to rest inadvertently on the ground or other lower level". A fall is an accident, it can be a slip or a trip, and causes may be environmental (for example, around the home, or in the garden, or when out and about) or personal (for example, due to weak or fatigued muscles, arthritis, changes in vision, fear of falling or dizziness).

Presentation Overview

- How can we reduce environmental hazards associated with falls?
- o What personal factors can lead to falls occurring?
- How can we simplify daily tasks and conserve energy for daily activities?
- What to do if a fall occurs?

Environmental Hazards – the top 10 falls hazards

- 1. Slippery surfaces
- 2. Obstacles in corridors
- 3. Poor lighting
- 4. Floor mats
- 5. Footwear

- 6. Climbing ladder / step ladder / chair
- 7. Bath
- 8. Uneven, broken or loose pathways
- 9. Trailing cords
- 10. Steps / stairs

Studies have found that just making small changes to your environment can significantly reduce your falls risk.

Floor Hazards

- Wipe up spills be mindful to look out for spills, eg around the pet's water bowl.
- Floor surfaces don't polish floorboards, watch out for talcum powder on floors, make sure carpets are not frayed or a possible trip hazard. Mats and rugs can have corners turned up and if you are experiencing some difficulty lifting your toes, or if you are carrying something and suddenly change direction, then that mat becomes something that trips you up.
- Keep walkways clear.
- Electrical appliances eg small heaters hide electrical cords under furniture or around skirting boards.
- Changes in floor level eg from bathroom to hall, or from carpet to kitchen, there is often a lip – there are wedge strips that can be used to prevent trips.

Lighting

- Ensure adequate lighting (75W globe recommended), there are vision changes with age ie difficulty judging depth and contrast.
- \circ Leave lights on at night eg when visiting bathroom during the night, use lamps.
- Light switches should be easy to reach.

- Reduce glare.
- Make obstacles or hazards stand out eg glass coffee tables can be a hazard, use a contrasting colour to your floor.

Bathroom

- Ensure toilet is easy to get up from install weight-bearing grab rails (not towel rails) or over-the-toilet aid.
- Safety of getting out of shower use shower chair/stool, grab rails, shower bench for transfers.
- Non-slip mats to reduce slipping
- $\circ\,$ Proximity of bedroom to toilet an option is to use a bedside commode, bottle or urinal
- o Bathroom modifications
- o Equipment







Around the house

Furniture

- Bed and chair make sure these are firm enough and high enough to get up from easily, raisers (called elephant feet) can be purchased to increase bed or chair height, this can reduce strain on your shoulders and wrists.
- Position and safety of furniture keep any walking aid close to where you are lying or sitting for when needed, look out for electric blanket cords or bed sheets getting caught up. Bed sticks/poles are useful to hold on to when standing up until you are steady (and hold when turning over in bed)



Steps / Stairs

- Rail or stair lifts, or ramps. Edges easily identified.
- Consider fatigue.

Pets

Reduce falls risks.

Outside

- Don't leave things lying around the garden like hoses retractable hoses available.
- Keep outside paths in good condition.
- Eliminate shadows across paths if possible.



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- Access into the home install easy to open doors, beware of screen doors closing on you, catching shopping bags etc.
- Adequate lighting.

Outings

- Go out when you have most energy / fewer crowds.
- Transport considerations disability parking permits, trains sit in the side section ie no stairs – buses, ask driver to wait until you are seated, use an electric scooter or a wheelchair for distances when shopping.
- Take any walking aids, glasses or hearing aids.
- Pay attention to your surroundings it is recommended that you scan four paces ahead for changes in surfaces etc.
- Plan the outing and rest breaks.
- Consider how to manage shopping use of carts, shopping delivery services.

Footwear and Clothing

Shoes

- Supportive, well-fitting shoes with low heels and non-slip soles.
- Fastening to hold the foot.
- Thin, firm midsole for your feet to feel the ground.
- Not worn, and support the foot in a good position.

Clothes

- o Non-restrictive.
- Not too long or loose fitting.
- No loose cords.

Personal Factors

- General medical issues dizziness, light-headedness, some medications can be an issue (a combination of 4 or more medications can increase your falls risk), bone health – how to reduce your risk of a fracture.
- Fear of falls.
- Vision have eye tests regularly; make sure your glasses are clean!!
- Sickness or injury.
- Cold intolerance muscles are weaker when cold; wear layers.
- Personality do you rush, are you a multi-tasker?
- Fatigue.
- Physical ability and activity.

MAKING THINGS EASIER

This is when we talk about fatigue and conserving energy. It is the same information that is given to people with heart problems or respiratory problems or anyone dealing with energy conservation.

Four Principles of Energy Conservation

Pacing

 Work out a baseline of activity that is comfortable for you ie not overusing those weaker muscles that are at risk of harm or damage. Signs of overuse are twitching, pain, weakness, a feeling of heaviness, spasm – all signs that muscles need to rest, and for some it may be for either a few minutes, or others they may need to lie down



for an hour, it is very individual. You may just have to change your activity to something using different muscles. Using a diary is useful, you can note how long you performed say gardening (eg 30 minutes) before you experienced some symptoms which meant it was too long a period, and so the next time you could reduce the time to say 20 minutes; particularly if you are getting even more than normal fatigue, this a sign that you need to cut back.

- Break activities into smaller steps, with rest periods eg vacuum one room per day.
- Listen to your body don't rush!

Planning

- Schedule your daily activities to use your energy wisely.
- Stick to time limits eg 20 minutes gardening.

Prioritising

• Eliminate non-essential tasks where possible eg shop on the internet, have shopping delivered, hire a cleaner, and a gardener to do the lawns.

Positioning

- Sitting uses less energy than standing it gives your leg muscles a rest eg sit to chop vegetables.
- Keep items in easy reach reaching and bending reduces your balance.
- Consider modifying the way you do things.
- Use equipment eg transfer bench little changes can make a big difference.

Some practical ideas

- Have items handy eg chair outside shower, put on terry towelling robe to dry yourself and have clothes there ready to get dressed OR if cooking, having everything ready in one area and then sit down to chop and peel and cook; a breakfast station or ironing station where everything is in one place.
- Sit where possible eg when gardening, use a kneeler which doubles as a seat, or when grooming pets.
- Avoid awkward postures bending and reaching, take that extra step to be closer and turn your feet to be right where you need to be. To reduce bending you can get a pick-up stick or use a toe wiper when sitting down, long-handled pan and broom, long-handled everything for the garden, long-handled stocking aids, folding/wall mounted clothes lines. Back up to sit down into a car, then lift legs in from a sitting position rather than trying to balance on one leg.
- Stay at ground level ie the higher you go, the harder you fall so getting up high is NOT a good idea.
- Pace yourself rushing is a real problem eg when the phone rings, let it go to voice message or carry a cordless or mobile phone (this is also useful if you do have a fall because you can phone somebody for help). Changing directions suddenly causes greater falls risk, think about your feet!
- Simplify where you can, use short cuts eg frozen vegetables, clothes that don't need ironing, have shopping delivered.
- Consider aids eg tray mobiles or laundry trolley to carry things from the kitchen to the lounge room. The Independent Living Centre is a great source of information about products; if you find some task difficult, you can phone them and speak to an occupational therapist for advice on what product might be helpful for you.
- Avoid dual tasks (and lifting).



If a fall happens

- Lying on the floor can cause problems without help you can get cold, pneumonia, miss medication etc.
- It is important to make a plan of what to do in the event of a fall: *Raise the alarm* – carry a mobile phone, wear a personal alarm pendant or wrist band which can be pressed to alert the monitoring company who will call your nominated person to come or they can call an ambulance. *Providing access* – a box outside with a combination lock can store your house key to allow access for ambulance paramedics.



Getting up from the floor if you have fallen

- o Calm down
- Check your body
- Roll onto your side
- o Crawl over to the chair
- o Put your arms up onto the chair
- Bring stronger knee forward and put that foot on the floor
- Push up, pivot your bottom around
- o Sit down

If you cannot get up

- o Do not panic.
- Think through all possibilities for raising the alarm and getting up.
- Try to stay warm.
- Gently move around to reduce pressure.

Questions

It was asked if others experienced muscle cramps, many in the audience did and the advice was to take magnesium and potassium and keep hydrated. It is a sign of muscle fatigue and overuse.

Alice told us of a small torchlight that she has attached to her walking stick which is very handy when walking in the dark etc. The small torches are available from most \$2 shops.

Anne O'Halloran explained how Technical Aids for the Disabled (TAD) helped her solve a problem she had with her garbage bin, they designed a special gadget that had four wheels to make it easy for Anne to push it. They are mostly retired engineers who design and make products to solve problems for disabled people. You only have to pay for the components of the 'gadget'.

Anne Buchanan told us of a water bottle holder that is made for push bikes and can be attached to your walker, it is available from Kmart.





Finally, when the topic arose of walking-stick rubber tips being slippery when going from outside to inside, Anne and Nola showed members the type of tips used on their sticks for stability. They are called Flexyfoot ferrules – they come in various sizes and are available for purchase from:



Advance Rehab Centre, St Leonards. Phone: 02 9906 7777



Member Shirley Roach wrote recently wishing to share some information with fellow members.

I've learnt about (and am using) a product which I thought some members may be interested in trying so wanted to let you know. It's called "Pea Protein Isolate" – all green vegies, especially peas, by "Nature's Goodness" and another by "Vital" – both very good.

In September I had a very bad fall and the dietician in hospital said I needed building up (at 40 kg, I'd agree). She wanted me to take some milky drink but I'm allergic to dairy.

The chemist sourced this for me on the 'net – I've used both brands (Health Food stores stock it as well) for about 4 weeks now and already feel better than I have in 5 years at least! I use 2 tablespoons in a glass cup of water once or twice a day. Using just a 450 gm container is worth a try. I do eat a lot more greens, especially peas, as well.

My left hip (already skin and bone for 65 years) has filled out a little! I've only got 27% sight but it looks better to me! I've a lot less general pain except for the right shoulder with the torn tendon, and it isn't so painful pushing my wheelchair. My fatigue seems less – I still have a rest each arvo but don't fade by the wayside so much. It helps with weight management, has no chemicals, dairy/lactose, soy, gluten etc.

I really hope some who feel the need of a bit of help may want to try it and gain the benefit I have (it's yum to drink too).



Update on Clinical Practice Workshops - Final 2 Sessions

Polio Australia is very pleased to be partnering with Rotary District 9685 to bring this series of FREE clinical practice workshops to allied health professionals wishing to learn more about management of the late effects of polio (LEoP). The workshops are driven by best-practice research from Europe and the USA and are open to all health and allied-health professionals.

Gosford

Thursday, **28 April 2016** : 1:00 pm - 4:00 pm

Thursday, **5 May 2016** : 1:00 pm – 4:00 pm

Conference Centre, Gosford Hospital, Holden Street

Narrabeen

The Tramshed Hall, 1395a Pittwater Road

Who Should Attend?

Allied and other health practitioners such as: physiotherapists, occupational therapists, orthotists, exercise physiologists, nurses, podiatrists, speech pathologists, dietitians, social workers, case managers, and anyone else who is interested in knowing more about the post-polio body.

How Can You Help?

If you live in the above regions and are consulting any health professionals in your local area, please be sure to let them know about the workshops and encourage them to register to attend.

For more information, visit: www.poliohealth.org.au/workshops

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Remembering Polio NSW through a Bequest

Would you like to support Polio NSW by remembering the organisation in your Will?

Over the past 26 years, thousands of polio survivors have benefited from Polio NSW either through their membership or through assistance that the organisation has provided. Polio NSW owes an enormous debt of gratitude to the generosity of people who have made donations or bequests to assist with the continued development of its services.

Why leave a Bequest to Polio NSW?

Polio NSW does not receive any money from government departments or other entities. The organisation depends almost entirely on donations and bequests from members. Polio NSW has grown into the organisation that it is today because of the support of the many people who believe in its purpose and objectives and who have been committed to ensuring its future through the giving of their time and/or by their financial support.

To sustain and develop Polio NSW into the future, we need your assistance. Through a bequest in your Will you will be able to ensure that the work of Polio NSW will continue for the benefit of polio survivors.

In particular, your bequest can help to:

- maintain an effective and viable organisation;
- provide for the employment of office personnel to relieve the workload of ageing polio volunteers;
- assist in developing an effective communication network;
- ensure the continuation of support at the local level;
- develop further services for polio survivors and the health professionals who care for them.

What to do

In consultation with a solicitor or adviser, consider making a bequest to Polio NSW in your Will and determine the type of bequest which best suits your circumstances and wishes.

For your information, Polio NSW is incorporated under the Associations Incorporation Act, is registered with the Australian Charities and Not-for-profits Commission, and is an authority holder under the Charitable Fundraising Act. The Network is recognised by the Australian Taxation Office as a Public Benevolent Institution and endorsed by them as a Deductible Gift Recipient (Number 90 039 932 667).

If you decide to include a bequest to Polio NSW and are willing to let us know, we can thank you personally for your generosity and forethought. If you would like any further information, just get in touch to see how we can help. Phone us (02 9890 0946), write to us (PO Box 2799, North Parramatta NSW 1750) or email us (office@polionsw.org.au).



Support Group Change

The Sutherland Support Group Convenor, Ruth Hatton, reminds us that they now meet at **CLUB MENAI**, 44 Allison Crescent, Menai, on the 1st Wednesday of each month at 2 pm.



Book Review - "The Polio Paradox" by Dr Richard L. Bruno by Susan Ellis

This book has only recently come to my attention when searching the 'net for useful polio information, and I was surprised to find that it had been written in 2002. Many of our members may already be familiar with Dr Bruno's book or may know Dr Bruno from his well known article "The Ten Commandments for PPS" (this can be viewed on <www.poliohealth.org.au/pps-the-australian-experience/>) or for his advice – "Conserve to Preserve" and "If anything causes fatigue, weakness or pain, don't do it (or do less of it)".

For more than 30 years Dr Bruno studied and treated nearly 6,000 polio survivors. Some of his research was in collaboration with his late wife, Dr Nancy Frick, herself a polio survivor. Dr Bruno is a psychophysiologist, he himself has multiple sclerosis and uses a wheelchair.

On further searching I found that Dr Mary Westbrook reviewed the book in our *Network News*, Issue 56, December 2002:

Book about the puzzles and paradoxes of polio

In June 2002 Dr Richard Bruno's book, "The Polio Paradox", uncovering the hidden history of polio to understand and treat 'post-polio syndrome' and chronic fatigue, was published. It is full of fascinating little-known details about the history of polio, much useful information about relieving post-polio symptoms and hunches e.g. as to how polio and chronic fatigue syndrome may be related and why polio survivors seem less likely to be diagnosed with Alzheimer's disease. The many paradoxes or seeming contradictions of the polio experience are highlighted through the book e.g. the extreme exercises and therapies that helped polio survivors to appear 'normal' set the stage for PPS and are the opposite of what you need to do to manage PPS today. In the 1980s, doctors were ignoring and rejecting the same polio survivors whose plight had riveted the attention of the world's medical community and spurred it to action just thirty years before. Bruno says that to take the leap of faith to cope with PPS you should read the words POLIO SURVIVOR again and again taking in the breadth and depth of their meaning. If you can remember all you have survived and appreciate how you have thrived in spite of polio, there can be no question that you have the ability to make the physical and emotional changes necessary to survive and thrive with PPS.

Dr Mary Westbrook

I found Dr Bruno's book very informative, it explains the whys and hows of contracting polio and of its effects on our brains and bodies. It has lots of practical advice based on research, experience and sometimes just common sense. At times I found some of his recommendations difficult to take 'on board' but overall it has the most relevant information that I have found to date. As with most information that we as polio survivors come across, you take from it what is relevant to you – try some new ideas or suggestions and then make up your own mind what works for you.

I myself have made some changes as suggested in Dr Bruno's book which are relevant for me and found them useful and constructive. I think it will be a go-to book for when new issues crop up in the future.

Available from Fishpond.com.au \$34.48 (free shipping) or www.amazon.com.au to download to your Kindle for \$19.99.

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The following articles are reprinted from the Newsletter of IDEAS, January/February 2016

No Inferest Loan Scheme (NILS)



The No Interest Loan Scheme (NILS) provides individuals and families on low incomes with access to safe, fair and affordable credit. Loan amounts are between \$300 and \$1,200 for essential goods and services such as fridges, washing machines and medical procedures. Loans cannot be used for cash, bond, rent arrears, debt consolidation, holidays or bills. Repayments are set up at an affordable amount over 12 to 18 months.

NILS is offered by more than 250 local community organisations in over 650 locations across Australia.

What are the loans for?

Loans are available for the purchase of essential goods and services. These may include:

- Household items like fridges, washing machines, stoves, dryers, freezers and furniture.
- Some medical and dental services.
- Education essentials such as computers and text books.
- Some other items as requested.

Do you qualify for NILS?

To qualify you must:

- Have a health care card/pension card.
- Reside in your current premises for more than 3 months.
- Show a willingness and capacity to repay.

How does it work?

- 1. Enquire about a loan now or call 13 NILS (13 64 57).
- 2. Bring your documentation to a meeting with the local loan provider.
- 3. Your loan application is assessed.
- 4. You are informed of the outcome of your loan application and agree repayment terms.

For more information: Website: <www.nils.com.au> Phone: 13 64 57

Information sourced from NILS website



What is AIDER?

AIDER is a one-off FREE service, supporting residents to live safely and confidently in areas where bush fires may start. The AIDER program offers a one-off FREE service to reduce bush-fire hazards around your home. The property must be bush-fire prone, meaning an area of land that can support a bush fire or is likely to be subject to bush-fire attack.

Who is eligible?

Aged residents and residents with disabilities who have limited domestic support from family, relatives, friends or other services.

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AIDER service may include:

- Thinning vegetation.
- Removing leaves, sticks and fallen branches.
- Trimming branches from around and overhanging the home.
- Mowing or slashing long grass.
- Cleaning gutters.

To request an assessment of your property call: 02 8741 4955

Website: <www.rfs.nsw.gov.au/plan-and-prepare/aider>
Phone: 1800 679 737
Information sourced from NSW Rural Fire Service website and flyer

Smoke Alarm Subsidy Scheme

It can take less than three minutes for a fire to completely engulf a room and the risk of fatality increases as much as 60% without an effective smoke alarm. Additionally, Fire and Rescue NSW research shows that between 2000 and 2014, 56% of fire fatality incidents had no smoke alarm present, with the vast majority of these fatalities occurring between midnight and 6:00 am. For deaf and hard-of-hearing people who cannot hear a smoke alarm, specialist alarms that include a strobe light and pillow shaker are available at the cost of \$20.

If you live in NSW and experience severe to profound hearing loss, or know someone who does, apply to receive a subsidised alarm by contacting the Deaf Society at:

Website: <www.deafsocietynsw.org.au> Phone: 02 8833 3600 or 02 8833 3691

Life Tec



In partnership with Independent Living Centres Australia, Life Tec has designed a free online National Equipment Database (NED). NED provides free information on over 10,000 assistive technology products and equipment options across Australia. Users can browse by product topics, search for suppliers, create shortlists, and compare products to find a practical solution to everyday life activities.

Website: ilcaustralia.org.au/search_category_paths

UberASSIST



Uber Australia has launched a new service called UberASSIST. UberASSIST is designed to provide additional assistance for users. Top driver-partners receive training and knowledge of safety requirements and can accommodate folding wheelchairs, walkers, and collapsible scooters. The UberASSIST driver training has been developed by the Open Doors Organisation (USA), along with consultation from the Australian Network on Disability (AND).

Uber doesn't yet cater for passengers requiring lifts or accessibility ramps, but is looking for people owning wheelchair-accessible vehicles to partner with Uber, so this service can be offered in the near future. To access UberASSIST, download the Uber app and enter the code 'ASSISTAU' in the promotions tab.

Website: <www.uber.com>





New all-terrain wheelchair gives everyone access to Dandenong Ranges National Park

To celebrate International Day of People with a Disability, all visitors to Dandenong Ranges National Park will now be able to enjoy trails in the park thanks to a motorised all-terrain wheelchair – called a TrailRider. A modified version of a Canadian invention, the motorised TrailRider was created by Parks Victoria and is the first of its kind in the world.

TrailRider all-terrain wheelchairs are a cross between a rickshaw and a wheelchair and can handle more rugged bush trails where conventional wheelchairs cannot go.

The motor on the chair makes it easier to manoeuvre the chair over rough trail surfaces and makes it easier for visitors with mobility limitations to access steeper and longer trails than ever before.

"Everyone has the right to enjoy the benefits of being in nature and we want to help everyone to be active in our parks. This is just one way we are making this possible", said John Kenwright, Community inclusion Coordinator, Parks Victoria.

"The TrailRider really opens up park areas that people with limited mobility may never have been able to see or experience."

The TrailRider has recently been trialled by a YMCA Recreation camp in the Dandenong Ranges for children with disabilities. Having a TrailRider based in the Dandenong Ranges will make it much easier for the YMCA, other organisations and individuals to regularly access a TrailRider chair to explore parks.

The TrailRider is located at *Grant's on Sherbrooke* café at Grant's Picnic Area in Mount Dandenong National Park. It can be booked by calling **03 9755 2888.**

|--|

Key Facts

- For work on improving access to parks, including making TrailRiders available, Parks Victoria won a 2015 National Disability Award.
- TrailRider all-terrain wheelchairs are just one of the facilities and programs supported by Parks Victoria to ensure parks are accessible to everyone.
- There are now 11 TrailRider all-terrain wheelchairs available in the Grampians National Park to assist visitors with disabilities to explore the many spectacular park trails using the TrailRider chairs.
- There are now ten child and adult beach wheelchairs available to explore Victoria's coastal parks.
- Trained volunteers from the Sherpa Volunteer program are available to explore Victoria's coastal parks.
- Thirty-eight of Victoria's most visited parks now have more comprehensive park access information provided to help visitors plan their park visit and park activities.

Website: <www.parks.vic.gov.au/visit/improving-park-access-for-all>

Phone: 0448 572 342

Information sourced from Park Victoria Media Release



SCIA Independence Expo

When: Friday 15 April and Saturday 16 April 2016, 10 am – 4 pm

Venue: Australian Technology Park, Sydney

Cost: Free to attend, register at www.scia.org.au/expo or 1800 819 775

Spinal Cord Injuries Australia (SCIA) is holding the 3rd biennial SCIA Independence Expo to tackle the #1 issue for people with physical disabilities – enhancing their independence. The event showcases how people with physical disabilities can live as they wish in their own homes, workplaces and communities.

The SCIA Independence Expo will give people with physical disabilities the opportunity to find new ways to enhance their lives with amazing products, equipment and technology on display. Information-packed demonstrations and workshops on issues that matter to them. People can also explore lifestyle options like travel, sport, art and music. There will be opportunities for people to socialise and enjoy fun activities over the Expo's two days.

Thanks to the support of sponsors like PME Auto Conversions, the SCIA Independence Expo is free for anyone to attend – people with disabilities, family, friends, carers, professionals working in the disability, healthcare or community service sector or students embarking on their career in the sector. People registering to attend at **www.scia.org.au/expo>** or **1800 819 775** will go into the draw to win a \$500 gift card.

Funding will also be available for people with physical disabilities to assist with the travel, accommodation and care costs required to attend the SCIA Independence Expo.

Contact: Claire Beaver, Marketing Manager, Spinal Cord Injuries Australia – 02 9356 1121

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2016 Polio NSW Seminar Program

Wednesday 18 th May	Northcott Society 1 Fennell Street North Parramatta	Managing Pain Full details on pages 2 and 3
Annual General Meeting Date TBA	Burwood RSL Club 96 Shaftesbury Road Burwood	Annual General Meeting and Seminar Details to be advised in upcoming issues

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Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	02 9890 0946
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	02 9890 0946

Have You Included Your Polio Details on 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 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <www.polioaustralia.org.au>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.

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Polio NSW Inc



March 2016-Autumn Edition

A Taste Of Things To Come

The following <u>abstract</u> is one of a selection of presentations in this edition which make up the Program for the *Australasia-Pacific Post-Polio Conference – Polio: Life Stage Matters* from 20-22 September in Sydney. Check the website for all details: <u>www.postpolioconference.org.au</u>, including a 'Call for Abstracts' which closes 31st March.



Anaesthesia for the post-polio patient

Dr Christine Ball Specialist anaesthetist Department of Anaesthesia and Perioperative Medicine Alfred Hospital, Melbourne, Victoria, Australia

The patient preparing for a surgical procedure is embarking on a journey, one which will include a large team of people, all focused on the same goal – the complication-free recovery of the patient. The anaesthetist's role is this team is often poorly

Register Now

understood, both by patients and by other health professionals. Not only will the anaesthetist provide a painless route through the surgery itself, but they will also be an important contributor to the optimisation of the patient's health – preoperatively, intraoperatively and postoperatively.

For the post-polio patient, communication with the anaesthetist preoperatively is essential. Apart from a general medical and surgical history, the anaesthetist will require specific information about neurological and muscle health, fatigue, sleep disordered breathing, ventilatory requirements and chronic pain issues. They will also perform a focused examination looking particularly at the respiratory system, musculoskeletal deformities and the airway. This interview is an important place for the patient to ask questions and have their particular concerns raised and addressed.

The anaesthetist will also communicate with any other health professionals involved in the patient's care. From them they will obtain recent test results, such as respiratory function tests, sleep studies and cardiac echocardiograms, an overall medical history and an understanding of the patient's ongoing treatment plans. Then together they can plan the best possible approach for the particular patient and the most appropriate postoperative monitoring, respiratory care, pain management and rehabilitation.

This presentation will explain the issues presented to the anaesthetist when managing the post-polio patient. Given the diversity of the audience, hopefully this will then facilitate improved communication between anaesthetists, patients and the rest of the medical and allied health professional team. The ultimate goal of this talk is improved patient-centred care, allowing each individual patient to feel that their needs are recognised, acknowledged and appropriately managed.

SAVE

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2016 Australasia-Pacific Post-Polio Conference Polio - Life Stage Matters

National Patron: Dr John Tierney, Ph.D. DAM

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Polio Oz News

Polio Australia

Representing polio survivors throughout Australia

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Polio This Week

From the President

At

of

lived

Both

Australia

were saddened

to learn of the passing of one

Lisa Cameron.

Lisa contracted

Polio in 1929

aged three and

Thomas and I

represented

to

our

benefactors,



Dr John Tierney President

Polio Australia at her funeral recently. You can read more about Lisa's contribution to Polio Australia's work on page 6.

Polio Australia is now half way through the running a pilot series of Clinical Practice Workshops for professionals health in the northern Sydney region. This is due to the generous support of Rotary District 9685 which has provided \$20,000 dollars in funding and is assisting with resourcing the workshops. These Workshops continue to be very well received by the participating health professionals, who have provided very positive feedback. Read more on page 4.

Polio Australia Board Fundraising and Rotary Club Liaison Director, Sue Mackenzie (Queensland) is off to a flying start and is already several fundraising arranging events in 2016. Sue is also Rotary Club managing our Speaker's Program comprising 22 volunteers, and has provided them with advice and resources. If you would like to join our panel of Rotary Club Speakers, and receive our Speaker's package, just contact <u>Mary-ann</u> at Polio Australia.

I would also like to acknowledge and thank Fran Henke for her media activities on our behalf during her brief time on the Board as an Independent Director for Communications and Media Relations. Fran's resignation letter stated that "While polio might have taken away some aspects of life, it gave me a love of reading, writing, making books and painting. I wish to focus on writing fiction, which takes total concentration, and to enjoy life mv husband Ian.' with We certainly wish Fran well in her creative pursuits, some of which can be seen on her website.

Polio Australia's three day Australasia-Pacific Post-Polio Conference being held from 20-22 September 2016 in Sydney, has just reached significant а milestone with the 100th delegate registration. If you plan to go to this highly informative Conference about the Late Effects of Polio, please register soon. Apart from educating health professionals, we want as many polio survivors as possible to benefit from this life changing event.

As you are all very well aware, Polio Australia receives not one cent in government funding for the great work that we all do on behalf of Australia's 400,000 polio survivors. We are increasingly dependent on private donations. Recently we have turned our attention to Bequests. In January, Mary-ann and I had dinner with John Jeffreys OAM, former National Director of CBM Australia and Founding Board member of Vision 2020 Australia. During his 33 years with CBM, John was a fundraiser, very successful particularly in the area of Bequests. John has been providing Polio Australia with advice on how to go about our own effective Bequests Program. We have now received private donations to cover the cost of a part-time Bequests Officer to advance this fundraising initiative.

So, when people update their Will, we would like them to consider supporting the work of Polio Australia with a Bequest. For example, my Will states that my inherited Commonwealth Bank shares be passed onto Polio Australia for the support of polio survivors. Perhaps you could too? More information can be found on page 5.

John

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Polio Oz News

From the Editor



Mary-ann Liethof Editor

Welcome to the first edition of Polio Oz News for 2016. This promises to be an exciting and productive year for Polio Australia.

In "A Taste Of Things To Come", I have featured four abstracts randomly selected from dozens we have received for the Australasia-Pacific Post-Polio Conference being held in Sydney in September this

year. This will truly be a Post-Polio Conference like no other. We are incredibly fortunate to have secured a veritable 'Who's Who' of post-polio experts from around Australia, Europe, the USA, and other parts of the world, to present at this Conference.

Who should attend, I hear you ask? This unique Conference aims to provide a broad range of professionals gold with health standard diagnosis, treatment, and management strategies to provide the best care possible for post-polio patients. Having said that, polio survivors, their family/carers/friends will also gain unprecedented access to information to assist them with self-management techniques. In short, there is something for everyone! DON'T MISS OUT on this not-likely-to-be-repeated education opportunity. Register now!

While John remembers Lisa Cameron, another sad farewell goes out to Dennis Lloyd, Chair of the Mornington Peninsula Post-Polio Support

Blessings In Disguise

"I'm a polio survivor (now 82), after contracting polio at age 17 at Geraldton in 1951. Both my legs are still paralysed. I used crutches for 53 years and for the past 12 years or so I've used an electric wheelchair.

I've written a short booklet titled "Blessings in Disguise". *It gets this name from the quotation by Oscar Wilde:* "What seems to us as bitter trials are often blessings in disguise."

It outlines that, until five years ago, I regarded my disability (a "bitter trial") with feelings of bitterness and regret, resulting in regular bouts of depression. However, after a Big Picture viewpoint of my life in 2011, I suddenly realised that polio was indeed a blessing in disguise for me.

For any polios who are still suffering depression through their disability, I am prepared to email my story to them."

Click on Kevin Lehane to send him an email.

Group in Victoria. Dennis certainly featured during my time with Polio Network Victoria. He had that quintessential determination which enables polio survivors to achieve great things, in spite of a myriad hurdles. He is remembered by Fran Henke on page 8.

The update on the Polio Australia and Rotary District 9685's Pilot Post-Polio Clinical Practice Workshop Series can be found on page 4. The most recent North Rocks Workshop held on 10th March, takes the numbers of health professionals upskilling themselves to approx. 80, which will be a fantastic boon for their post-polio patients.

Personally, I love a good piece of sculpture, so I was delighted to find an article on "*The Spanner Man*"—see "*Post-Polio In The News*" on p9. This is the amazing story of John Piccoli from rural Victoria, who is producing huge sculptures out of spanners, of all things! Make sure to watch the video link to see how he has geared up his workshop to move things around. We see the word 'inspirational' a lot these days, but John is the 'real deal' in my book.

I have also included a few clinical studies I've found which should be of interest to many, especially if taking bisphosphonates for osteoporosis, paracetamol for hip osteoarthritis pain, or are looking to shed a few kilo's. (Aren't we all?)

This is, of course, all topped off with information on the Polio Eradication campaign.

I hope you enjoy these offerings.



Thanks Peter!

Polio Australia and Polio NSW pro-bono auditor Peter Roebuck retired in 2015. Gillian Thomas recently presented Peter with a plaque in grateful acknowledgement and recognition of his valued assistance to the polio community over 24 years.



LEoPClinical Practice Workshop Series Update

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poliomyelitis

clients

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Penrith

Hornsby

Windsor

Hospital

2 Day St

Gosford

Holden St

Narrabeen

Penrith RSL Club 8 Tindale St

Mt Wilga Private Hospital

66 Rosamond St

Hawkesbury District

Conference Centre

The Tramshed Hall

1395a Pittwater Rd

Rotary a District 9685

Gosford Hospital

Rotary District 9685

partnering with Polio Australia

to deliver

Why We Vaccinate: a brief history of polio

Demystifying Late Effects of Polio and Post-

The Aging Polio Population: joining the dots

"Did You Have Polio?": identifying people

other allied health professionals to address

key concerns such as managing pain and

Polio Syndrome: what's the difference

of problems experienced in LEoP / PPS

who may be experiencing LEoP / PPS

fatique, and help with stability and

A Late Effects of Polio Case Study: Q&A

with local polio survivors and team care

Thursday 24 March 2016

Thursday

Saturday 16 April 2016

7 April 2016

1.00 - 4.00pm

1.00 - 4.00pm

Thursday 28 April 2016

Thursday

5 May 2016

1.00 - 4.00pm

1.00 - 4.00pm

9.30am - 12.30pm

Practical strategies used by physiotherapists, orthotists, and various

What is polio?: The pathophysiology of

3 hour Workshop Topics

Earn 2.5 CPD hours ~ Receive a Certificate of

- Attendance
- ~ Free PDF of 100 page
- resource "Managing Muscles and Mobility", and more . . .
- Refreshments provided

POLIO: IT'S NOT OVER Decades after the poliomyelitis epidemics in Australia, the aftermath of the disease is now becoming evident in our ageing 'polio population'. An estimated 400,000 people may be suffering the Late Effects of Polio (LEoP) or Post-Polio Syndrome (PPS). Do you know how to recognise these conditions in your practice?

CHRONIC ILLNESS WITH A DIFFERENCE There are many cross-overs in the treatment and management of other chronic diseases and LEoP/PPS, and there are also some very significant differences. If LEoP is not identified, the client can experience rapidly worsening symptoms due to inadvertently incorrect care.

YOU CAN IMPROVE THEIR FUTURE For many LEOP/PPS clients, biomedical and pharmaceutical treatments have limited efficacy. Polio survivors are turning their attention and hopes to allied health practitioners to help them improve their quality of life, and prolong their daily functional ability as they age. With a holistic approach to care and increased awareness within the greater health sector, LEoP/PPS clients can manage their symptomes live better, and and well symptoms, live better, and age well.

Registration: www.poliohealth.org.au/workshops Email: workshops@poliohealth.org.au

Ryde Royal Rehab 235 Morrison Rd	Thursday 26 November 2015 1.00 - 4.00pm	
ARC Health 3/41 Herbert St	8 December 2015 5.30 – 8.30pm	
Katoomba Blue Mountains District ANZAC Memorial Hospital Great Western Hwy & Woodlands Rd	Saturday 6 February 2016 9.30am - 12.30pm	
Wyong Wyong Golf Course 319 Pacific Hwy	Saturday 27 February 2016 9.30am - 12.30pm	
North Rocks Eorsight Foundation 241 North Rocks Rd	Thursday 10 March 2016 9.30am - 12.30pm	
	Royal Rehab 235 Morrison Rd St Leonards ARC Health 3/41 Herbert St Katoomba Blue Mountains District ANZAC Memorial Hospital Great Western Hwy & Woodlands Rd Wyong Wyong Golf Course 319 Pacific Hwy North Rocks Earsight Foundation	Royal Rehab 235 Morrison Rd26 November 2015 1.00 - 4.00pmSt Leonards ARC Health 3/41 Herbert StTuesday 8 December 2015 5.30 - 8.30pmKatoomba Blue Mountains District ANZAC Memorial Hospital Great Western Hwy & Woodlands RdSaturday 9.30am - 12.30pmWyong Wyong Golf Course 319 Pacific HwySaturday 27 February 2016 9.30am - 12.30pmNorth Rocks Earsight FoundationThursday 10 March 2016

P_{lio} Australia

- Be more aware and read up the literature. •
- Be aware who I put on a treadmill. •
- Attend Sydney Conference in September.
- Share information with Colleagues. •

This is definitely a fantastic outcome for their post-polio patients!

To find out more about this Clinical Practice Workshop series, and to access a vast range of additional resources for health professionals, go to **`Polio** Australia's Polio Health' website: www.poliohealth.org.au.



Although a couple of the 10 scheduled Workshops were undersubscribed and subsequently rescheduled (Narrabeen) or cancelled (Wyong), the forthcoming sessions being held in North Rocks, Hornsby, and Gosford are filling fast. Penrith, Windsor, and Narrabeen still have ample places available for health professionals.

This pilot Workshop series is a joint project between Polio Australia and Rotary District 9685, and facilitated by ARC Health's Principal and Neurophysiotherapist, Melissa McConaghy. Melissa is also a member of Polio Australia's Clinical Advisory Group.

When asked what they would do/ change as a result of having attended the Workshop, delegates' feedback included the following comments:

- Provide copies of slides to medicos unable to attend.
- Provide in-service to physio staff.
- Ask patients specifically about • their polio history.
- Look up further information.

L-R: Melissa McConaghy, Merle Thompson, Rotary Members John Isbister and Michael Small

CLINICAL PRACTICE FOR HEALTH PROFESSIONALS

Rotary

Pelio Australia

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 December to 29 January 2016:

Hall of Fame				
Name	Donation			
Dr John & Pam Tierney	\$2,000			
Lisa Cameron	\$15,000			
	Total—\$17,000			

General Donations

Names					
Anonymous	Jill Burn	Brett Howard	Hylton Gardiner	Liz Telford	
Mount Evelyn Community House Stitch and Craft Group					
Total—\$580					

Bequest Program

Bequest Charter





Polio: It's Not Over

Decades after the poliomyelitis epidemics in Australia, the aftermath of the disease is now evident in our ageing post-polio population. Up to 400,000 people may now be suffering with the Late Effects of Polio or Post-Polio Syndrome, with many unable to find health practitioners with knowledge of how to diagnose or manage the condition.

By leaving a Bequest to Polio Australia, after providing for family and loved ones, your support will continue to help raise awareness of the Late Effects of Polio and provide training and resources for both polio survivors and the health professionals who dedicate their lives to caring for people and managing their chronic health needs.

As we receive no government funding, we rely on Bequests and Donations to ensure people living with the Late Effects of Polio have access to appropriate health care and the support required to maintain independence and make informed choices.

So whether large or small, your Bequest will be valued greatly, because it will change the life of a person who is ageing with the chronic and often debilitating symptoms associated with the Late Effects of Polio. You will also be helping to educate health practitioners in this little understood condition.

Click on the photo to link to the brochure or contact Polio Australia for details: 03 9016 7678.

Did you know that three out of four Australians support charities throughout their lifetime, but only 7% of Australians include gifts to their favourite charities in their Will?

Vale Lisa Cameron: Benefactor of Polio Survivors



At Polio Australia we were saddened to learn of the passing of one of our great benefactors, Lisa Cameron—1926-2016. Lisa had a true Scottish heritage. In the 1830's, two Cameron brothers left Aberdeen in the Scottish Highlands to seek a new life in Australia. On board their ship they met two Campbell sisters and both couples were married when they landed in Sydney town.

The family moved to the New England area, where they lived and prospered for generations. Both Lisa and her brother attended private schools in Armidale and Lisa became a significant benefactor of both schools. This included the funding of scholarships for children whose families could not afford such an education. The esteem in which Lisa was held at the schools was marked by the attendance at her funeral of a principal and a senior executive from both schools.

Lisa contracted polio in 1929 aged three and lived to 89. Both Gillian Thomas and I represented Polio Australia at her funeral recently. We both first met Lisa over two years ago when she invited Gillian and I out to one of her famous morning teas at her home on Sydney

Harbour. There she presented us with a cheque for \$30,000 dollars for the support of polio survivors.

You would not have heard of Lisa, because she insisted that her funding of vital Polio Australia programs be anonymous. I now have permission to reveal that over the last two years she has donated over \$60,000 dollars to our cause. One of the very significant projects funded completely by Lisa was our world's best practice "*Muscles and Mobility"* resource for health professionals.

The following statement was read out at Lisa's funeral on behalf of Polio Australia:

"Lisa was a great lady whom we held in high esteem at Polio Australia and we have fond memories of the times that we spent with her. The 400,000 polio survivors in Australia and we as their advocates are so grateful for Lisa's generosity to our cause over the years. In particular, her funding of resources that have been of great assistance to Australia's polio survivors with the management of their condition. It is a lasting legacy that we will always cherish."

Jan Williams Speaks To Rotarians

Some of you will recall reading about Sue Mackenzie's fundraising success a couple of years ago through Rotary Club talks in Far North Queensland and, more recently, with her Fashion Fiesta fundraising event in Brisbane. Sue is now co-ordinating an Australia-wide project for Polio Australia by mentoring and encouraging interested polio survivors to speak at as many Rotary Clubs as possible, with the aim of sparking their interest in financially supporting Polio Australia's work. I have joined Sue in this quest, and on Tuesday 1st March, I attended a meeting of the Rotary Club of Albany Creek, Queensland, as guest speaker on behalf of Polio Australia.

The 15 minute presentation covered Rotary's involvement with polio in Australia, as far back as the 1920's, their ongoing involvement in assisting in the endeavours for the eradication of polio world-wide through vaccination programs, and informing them of the current and very real situation in regard to the Late Effects of Polio.

My presentation was enthusiastically received by the members of the club, and an animated 15 minute question time ensued. Club President, Ken Weston and President Elect Cherryl McNaught (*pictured to my right*), advised that their Club would like to be actively involved in assisting and will be in touch following their next Board Meeting.

I have made contact with 9 other Rotary Clubs and am hoping to get the opportunity to address their members in the near future.



Polio Oz News

A Taste Of Things To Come (cont'd from p1)

Sleep Hygiene – sleep as a trained behavior. How to improve duration and quality of sleep to improve health and wellness.

William M. DeMayo, M.D. Physician Physical Medicine & Rehabilitation Summit Medical Rehabilitation Pennsylvania, USA

By anyone's standard, the average person today has more "busyness" and less sleep than any time in history. Sleep often becomes a casualty of today's digital technology and media. Most individuals view sleep as a passive state ("falling asleep") rather than an activity ("going to sleep").

Instead of setting a healthy goal of 8 hours or more of sleep, many individuals set a target for sleep just above the point where they can not function well the next day. Unfortunately this does not account for the fact that effects of sleep deprivation usually occur over time. Additionally, quality of sleep is often poor due to the effects of stress on reducing percentage of deep sleep so that many individuals have reduction in both quantity and quality of sleep. Results can include chronic fatigue, poor productivity, irritability, weight gain, and exacerbation of painful conditions.

In this session we will discuss the topic of Sleep Hygiene – habits that can help anyone take control of their sleep patterns and quality of their sleep. We will look at sleep as a trained behavior.

While other circumstances such as pain, children/environment, and medications can all impair sleep, we will focus on the behavioral aspects of sleep that are most under the control of the individual and usually are the limiting factor in obtaining restful sleep over time.

Register Now





Post-Polio In The News

Polio: forgotten but not gone By Amanda Smith

Source: The Body Sphere (RN) -17 February 2016

Polio isn't yet eradicated from the world; it still exists in Pakistan and Afghanistan. Additionally, many Australians who contracted the disease as children are now experiencing a recurrence of symptoms. **Amanda Smith** reports.

If you were a child in the first half of the 20th century, you were at real risk of getting polio. As with other waves of infectious diseases—HIV, Ebola and now Zika—there was no cure, no vaccine.

"Parents were really terrified for their children", says medical historian Kerry Highley. "Nobody could tell them how to protect their kids".

Polio seemed to strike at random, without warning. "One day they'd have a healthy and happy child running around with their friends and the next day that same child could be lying feverish and sobbing with pain and paralysed".

It wasn't until the 1950s that polio and its transmission as a virus — via person-to-person



Gillian Thomas (centre) and family

contact through faecal material — started to be properly understood. In her book *Dancing In My Dreams*, Highley researched the (often bizarre) theories behind the cause of the disease. These included sharks, soft drinks, summer fruits, plant pollen and feather pillows.

"Some believed that sunstroke was the cause and others believed that it was domestic animals like dogs or cats", she says.

"There were some people who believed that if you handled money in a till or spoke on the public telephone that you'd definitely catch polio".

The breakthrough came with the development of vaccines. In Australia, mass polio immunisation began in 1956 with the Salk vaccine, although this was too late for the tens of thousands of children who already had the disease.

Read or listen to the full interview via podcast <u>here</u>. Interviewed are: Kerry Highley, author of "Dancing In My Confronting Dreams: the spectre of polio"; Dr John Tierney, President of Polio Australia; Gillian Thomas, President of Polio NSW; and Billie Thow, Tasmanian Polio Australia Board member.

Note: Kerry Highley (pictured) will be giving the Closing Plenary at the <u>Australasia-Pacific Post-Polio</u> Conference in September.



Vale Dennis Lloyd



Our friend and Mornington Peninsula PPSG chair, Dennis died this Llovd, morning (29/02/16). His wife Deirdre said he had been unwell over the weekend but fell in the bathroom this morning. Ambulance officers were unable to revive him. He was 83.

Dennis and Deirdre have been at the helm of our group for 20 years this year. Whenever anyone one of us was in hospital or in difficulties they have been the first on the phone with offers of help.

Dennis had polio during the war in the UK and worked in the printing industry most of his life, forced to retire when PPS kicked in.

He loved gardening but in recent years found it too hard on their steep block, even with the help of his scooter. He and Deirdre also loved extremely big dogs, owning a Pyrenean and more recently a Saluki.

We all will miss Dennis so much. He exemplified the dogged determination common to polios to continue doing what he wanted to despite being in acute pain. He has kept the group going in the way that suited us — informally, friendly but informative; producing the monthly newsletter with local and overseas polio news — not forgetting his sense of humour with the 'blue section' and the 'lavish' morning teas that feed our chat. Polio Oz News

Post-Polio In The News (cont'd)

The Spanner Man: Meet one of the world's most unusual artists By Emily Stewart

Source: <u>ABC 7.30</u>-14 January 2016

Three hours out of Melbourne, in the small farming community of Boort, is one of the world's most unusual artists. John Piccoli welds giant sculptures out of spanners — earning him the nickname the Spanner Man. His garden is littered with dozens of larger-than-life sculptures of mermaids, marlin, and even a full horse and wagon.

It all started when he leased out his mixed grain and stock farm after running it for three decades, from his wheelchair. "I got polio in 1949. So I have grown up with having the disability that I have got", Mr Piccoli said. "Once I leased the farm there was nothing really left to do, so something had to fill the void. And because these spanners happened to be in boxes in the sheds I thought I'll start by making them into something and it grew from that".

His wife Sonia said he started making furniture and soon moved on to large artwork.

"He came to me and said, 'Oh come and see what I've been doing in the workshop'", she said. "I go to the workshop and he'd made a beautiful coffee table out of the spanners".

John uses blocks and tackles in the workshop to move the heavy sculptures around.

He buys most of the spanners at swap meets around Victoria or by the 1,000 in batches from his local hardware store.

He has created more than a 100 sculptures — using more than a 100,000 spanners so far. John does not use plans or drawings and works only from memory. He said he had not made a mistake yet.

At around \$2 a spanner, John had to find a way to fund his sculpting, so he started letting visitors come through. With just 700 residents in Boort, the thousands of visitors who come to see John's work and then shop, eat and stay in town are providing a big boost for local business.

Boort Tourism Committee's, Paul Haw, has known John since school days and spent two years convincing him to let visitors come through. "I think the first year he had 700 people — it doubled every year, and now I think it's getting close to 10,000 people a year", Mr Haw said.

Luckily for Boort, John has no plans to stop sculpting. "The plan is I will weld up until the day I die, that's the plan," he said. "I don't intend to waste away in a nursing home for the last 10 years of my life. I'd love to die in the workshop while I am welding. That would be the ultimate".

Visit John's garden here. Read full article here.



Post-Polio In The News (cont'd)

'The most feared disease of childhood and adolescence' and 'a deafening silence': Polio and post-polio in Australia

By Frank B. (Ben) Tipton The University of Sydney

This is an excerpt of an article which was first published in the *Australian Review of Public Affairs* (www.australianreview.net) on 15 February 2016 and is reprinted with permission.

POLIO MEMORIES

'Uh, sorry, but what did you do to your leg?'

'Oh. Well, I had polio when I was a kid, and now, well, it sort of comes back to bite you, later.'

'Polio? What's that?'

'Oh. Well, it's a virus, attacks the nerve ends in the spine, so you can't use the muscles, and you get paralysed. You recover, some, but then, later, it sort of comes back, like I said, again. But you, you're only, what, in your thirties? So you wouldn't ever have had to worry about it, you'll have been vaccinated, like everyone.'

'Uh, um, well, yah, no, I guess. Still, I mean, for you, that's a bit stiff, you know?'

That conversation, in the physiotherapy rooms of a rehabilitation hospital in Sydney in 2006, left me bemused. My well-meaning fellow outpatient, then 42 was born very shortly after the last reported case of 'wild' pólio infection in Australia. He had been struck by a car turning illegally against a red light as he crossed a road in the crosswalk, and both knees had needed surgical reconstruction. Under instructions from his neurologist, the physiotherapists assigned him a program including time on an exercise bike and treadmill, workouts with a Swiss ball and leg lifts, all intended to strengthen his legs. I had been struck by polio in 1954, but after a long period of stability I had experienced increased difficulty walking and climbing stairs. Under instructions physiotherapists my neurologist, the from assigned me a program including time on an exercise bike and treadmill, workouts with a Swiss ball and leg lifts, all intended to strengthen my legs. To be honest I thought being blindsided in a crosswalk was a bit stiff, but I felt my own situation was a bit stiff as well, as I found myself repeating a process I had worked through 50 years before. Suddenly those 50 years seemed to weigh more heavily, with the realisation that awareness of the disease that touched so many of us had been so completely effaced for the next generation.

So I am intrigued to find three recent works that feature that old disease here in Australia, a history, a novel and an account of a broken family, all of them highly readable and Dancing rewarding. In in My Dreams: Confronting the Spectre of Polio, historian Kerry Highley aims to redress the 'scant attention' paid by social historians to what was once 'the most feared disease of childhood and adolescence' (p. 1). She begins with the first epidemic outbreaks in the early 20th century, but concentrates on the conflict over treatment in the 1920s and 1930s and on the research of the 1940s that led to the vaccines and the 'victory' over polio in the early 1960s. Very critical of contemporaneous medical and government leaders, she is quite willing to draw equally negative parallels with their descendants today. In The Golden Age, novelist Joan London takes an actual historical setting, a pub of that name in suburban Perth re -purposed in the early 1950s as a polio rehabilitation facility for children and the collected memoirs of its former patients, and uses them as an exotic backdrop for an imagined adolescent love affair. In Boy, Lost: A Family Memoir, journalist Kristina Olsson investigates her family history, a story that revolves around her missing half-brother, Peter. Taken from their mother by his violent father in 1950 when she makes her escape, Peter falls victim to polio as a young child, must cope with both the disease and ongoing abuse by his father, and finally locates the mother and her new family over 30 years later. In three very different genres, the books are closely connected by a shared theme: the impact of those now forgotten polio epidemics.

Extremely contagious and potentially fatal, polio reaped an annual harvest from the late 19th through the middle of the 20th centuries, with increasing peaks in Australia particularly in the years of the First World War (436 reported cases in 1916), the late 1930s (2,590 cases in 1938) and the early 1950s (4,940 cases in 1951) (Highley, Table 2, pp. 179–180). As such it posed extremely difficult problems for those charged with treatment of the victims. The next sections outline the features of the disease, its onset and spread and the conflict over early treatment. This leads to the process of recovery, rehabilitation and the psychological impact of the experiences of disease and survivorship. As the case of Olsson's half-brother shows, the story does not stop, and the final section looks at the long term effects of polio, commonly referred to as post-polio syndrome.

Read full article here.

Polio Oz News

Post-Polio In The News (cont'd)

Disabled passenger Anita Ghai says Air India made her 'crawl' on tarmac; airline denies claim

Source: www.abc.net/au/news-1 Feb 2016

A disabled passenger says she was forced to crawl on New Delhi airport's tarmac after Air India failed to provide a wheelchair when her plane landed, an allegation the carrier denies.

Anita Ghai, 53, a leading disability rights activist and academic, said she was left stranded after arriving in Delhi from the northern Indian city of Dehradun on Saturday evening.

After being helped down steps from the plane by airline staff and a friend, Ms Ghai said no wheelchair was available for her to reach the terminal-bound bus several metres away.

"We were kept waiting on the tarmac for half an hour before a passenger coach came to pick me up. I had to crawl on the tarmac to board the coach", Ms Ghai said.

"I kept on reminding the staff to arrange a

wheelchair throughout the journey but to my shock when we landed there was none and all they said was there were 'security reasons'".

Ms Ghai, who is confined to a wheelchair after suffering polio as a child, described the incident as shocking and embarrassing.

Air India denied the incident, saying there was a delay in bringing the wheelchair because the plane was parked in an outlying bay.

"We strongly deny the statement ... We at Air India give utmost importance to passenger's safety and comfort", it said in a statement.

It is not the first time India's state carrier, which has not made a profit since 2007, has been in the news for the wrong reasons. Last month, a London-bound flight with more than 200 passengers was forced to return to Mumbai after three hours in the air over a suspected rat sighting in the cabin. A plane carrying 160 passengers was forced this month to return to Delhi almost 30 minutes into a Milan-bound flight after smoke was detected in the cabin.

Read full article here.

New BPF Post-Polio Syndrome Guide

The British Polio Fellowship has a new online resource: "Post-Polio Syndrome a guide to management for health care professionals".

Research conducted by The British Polio Fellowship in 2012 determined that only 55% of GPs were able to diagnose the symptoms and 18% of GPs did not know how to manage PPS when diagnosed. Independent research conducted in September 2015 by YouGov revealed that only 7% of the British public were aware of PPS.

The aim of this publication is to assist GPs and other clinicians in recognising and managing PPS. After several years of stability, individuals can develop increasing weakness, fatigue and pain in previously affected or unaffected muscles, a general reduction in stamina, breathing, sleeping and/or swallowing problems and cold intolerance. These symptoms may sound familiar and misdiagnosis is common as PPS is not recognised as a factor.

Post Polio Syndrome



A guide to management for health care professionals



Click on the picture to download your copy.



Photo: Disabled rights activist, Anita Ghai (R)

Polio Oz News

A Taste Of Things To Come (cont'd from p1)

The benefits and dangers of social media in the care, treatment and management of Post-Polio Syndrome - an observational study.

John R. McFarlane President, European Polio Union

The phenomena of social media has caused an explosion of realisation of the problems being faced amongst world-wide communities of polio survivors, in particular those of the recognition of Post-Polio Syndrome. Facebook and Twitter, especially, have spawned a plethora of on-line support communities that concentrate on the problems, medical, social and economic, that affect the different and differing groups of polio survivors, their families, and carers.

Discussions range across many topics including life style choices and solutions, orthoses and their comparative use, comparisons of health systems as well as medical discussions where polio survivors discuss the merits, or otherwise, of medical practitioners, the lack of medical awareness in the medical community and in many cases on-line discussion of the particular polio survivor's problems in the care, treatment and management of Post-Polio Syndrome in the primary care environment.

This approach to peer support is having great benefits with this wide ranging information exchange often across continents but it has also highlighted many dangers and drawbacks whereby polio survivors demonstrate a trait to lay the blame for all complaints on Post-Polio Syndrome.



This study, drawn from observation and case study over a defined 12-month period covering peer support groups, moderated and unmoderated, based in Europe and the USA, will show how the use of social media (Facebook, Twitter etc.) can enhance the quality of life and independence of the polio survivor. How its use may be utilised by medical personnel from all disciplines regarding care, management and treatment; as well as how dangers of misinformation from any source, both accidental and intended, may be avoided.

It will also address the necessity for moderating peer support groups, reliance on single source authority and the growing problem of "devotees" gaining access to peer support groups and preying on polio survivors both financially, psychologically and sexually.

Register Now

Latest Disability Health Statistics

by <u>Kymberly Martin</u>

Source: Freedom2Live-29 February 2016



More Australians with severe disability report having poor health compared to those without disability. According to a new report from the Australian Institute of Health and Welfare (AIHW), more than half of Australians aged 15-64 with severe or profound disability rated their health as poor or fair, compared to 6 per cent of those without disability. This group were also twice as likely to smoke daily or start smoking before the age of 18 and had a higher prevalence of various long-term health conditions. Almost half reported doing no physical exercise and were 1.7 times as likely as those without disability to be obese.

As well, half of people under 65 with severe or profound disability had mental health conditions, compared with 8 per cent for those without disability, said AIHW spokesperson, Mark Cooper-Stanbury. Additionally, they were more likely to acquire a mental health condition before the age of 25. This group were also four times as

likely to have arthritis and half acquired the condition before the age of 45, compared with 37 per cent for those without disability.

Asian Women and Bisphosphonates

Asian Women on Bisphosphonates at Higher Risk of Atypical Femur Fracture By Anne Harding

Source: Reuters Health Information –29 January 2016

NEW YORK (Reuters Health) - Asian women are more than six times as likely as white women to sustain an atypical femur fracture while on bisphosphonate therapy, according to a new/y published study.

"When counseling women regarding long-term treatment with bisphosphonate drugs, physicians should realize that risk benefit considerations differ not just by underlying fracture risk and length of treatment, but also by race", Dr Joan C Lo, a senior physician and research scientist at the Kaiser Permanente Northern California Division of Research and one of the study's authors, told Reuters Health by email. Dr Lo previously reported the findings of the study at the ASBMR meeting in October 2015, <u>as reported</u> <u>by Medscape</u>.

Atypical femur fracture (AFF) is a complete fracture in the mid to upper femur occurring with minimal trauma, and is a rare complication of bisphosphonate use. The mechanism behind the association between bisphosphonates and AFF is not clear, but both treatment duration and recent exposure to the drugs are associated with AFF risk, Dr Lo and her team note in their report, published online January 6 in Bone.

"However, the overall rare occurrence of AFF events among the vast numbers of women receiving oral bisphosphonate drugs each year indicates there may be additional contributing factors", they say.

Epidemiological studies have suggested that Asian women are at sharply higher risk of AFF

when on bisphosphonate therapy. To better understand the risk, Dr Lo and her colleagues looked at 48,390 female Kaiser Permanente Northern California members 50 and older who started bisphosphonate therapy in 2002-2007 and were followed for at least three years. Nearly two-thirds of the women were white, and 17.1% were Asian. Most of the Asian women were of Chinese or Filipino ethnicity.

During follow-up, which lasted a median 7.7 years, 69 women sustained 73 AFFs. For non-Asian women, the incidence of AFF was 9 per 100,000 person-years of follow-up, versus 64.2 per 100,000 person-years for Asian women.

The median treatment time before AFF occurred was 5.5 years, and it was 5.7 years for white women, 5.4 for Asian women, and 5.1 for women of other ethnicities. All of the AFF cases occurred in women taking alendronate, and 92.9% were taking 10 mg/day.

"Asians have different bone structure (femur geometry and size) that may contribute to a higher risk of AFF in the setting of bisphosphonate use", Dr Lo said. "Bisphosphonate drugs may also affect bone metabolism differently in Asians".

"Bisphosphonate drugs are effective in preventing fractures and remain a first-line therapy for osteoporosis in women, including Asians. For women at high risk for fracture, the benefits of bisphosphonate treatment in the first five years far outweigh the very low risk of AFF", she added. "However, the risk of AFF increases with bisphosphonate treatment duration, and is higher for women of Asian race. Therefore, physicians should carefully consider the risks and benefits of bisphosphonate treatment beyond five years, especially in Asians".

Original Source: Bone 2016.

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Paracetamol Ineffective for Hip Osteoarthritis

Paracetamol Is Ineffective for Spinal Pain and Knee and Hip Osteoarthritis By David Felson

Source: Medscape.com—Evid Based Med. 2015;20(6):205

Context

While paracetamol continues to be recommended as an initial pharmacological treatment for osteoarthritis and to a lesser extent for back pain, increasingly trials and metaanalyses have suggested that its efficacy is minimal and some epidemiological evidence suggests that at high doses, paracetamol may be dangerous. Machado and colleagues carried out the most comprehensive meta-analysis yet of the efficacy safety of paracetamol and versus placebo for back pain, neck pain and knee and hip osteoarthritis pain.

Methods

The authors carried out a for comprehensive search randomised trials comparing and safety efficacy of paracetamol versus placebo for the aforementioned conditions. They registered their metaanalysis following PRISMA guidelines. Articles had to report pain and/or functional outcomes. Risk of bias and publication bias were assessed. For each treatment arm in each trial, the authors converted pain and function outcomes to a 0-100 visual analogue-type scale computed the and then difference between these treatments on this scale.

Findings

The authors found 3 spinal pain trials and 10 trials of knee and/ or hip osteoarthritis. For each of these disorders there was little heterogeneity across trial findings and the evidence was rated formally as of moderate to high quality. Paracetamol dosages in these trials were consistently over 3 g a day.

The authors found no effect of paracetamol on spinal pain in the immediate (<2 weeks) or short term (>2 weeks but <3 months) with placebo patients actually doing marginally better in terms of pain than acetaminophen patients (1.4 on a 0-100 scale (95% CI`-1.3 to 4.1)). Effects were the same for function. For osteoarthritis there was а modest effect of paracetamol with little heterogeneity across trials. In the immediate term, the paracetamol patients on average had an improvement compared to placebo of 3.3 on a 0–100 scale with the 95% confidence bound not extending up to the minimal clinically important difference for pain of 9 per 100. For short term, the effect was almost identical with the upper bound of the effect not reaching the minimal clinically important difference. Paracetamol-treated patients had no increase in adverse events other than an increase in liver function tests of unclear clinical significance.

Commentary

This meta-analysis is the most comprehensive yet to evaluate the efficacy of paracetamol at a high dose and is consistent with earlier study findings. One systematic review (osteoarthritis) reported that the paracetamol effect size for versus placebo was <0.2 SDs versus placebo on a scale where 0.2-0.5 is characterised as a small therapeutic effect. Nonsteroidal anti-inflammatory drugs at therapeutic doses have effect sizes of 0.3–0.5 using the same approach. This metaanalysis of short-term trial data did not include a comprehensive examination of toxicity which is better addressed in long-term observational studies.

Some data suggests that paracetamol at a high dose may inhibit cyclooxygenase, especially COX-2. Long-term observational cohort studies have reported that people who take paracetamol daily may be

at an increased risk of incident hypertension, deterioration in renal function and even myocardial infarction. It should be noted that no such risks have been reported for people who use paracetamol intermittently or at a lower dose. Also, paracetamol at a high dose may cause a drop in haemoglobin level, suggesting that this cyclooxygenase inhibitor may cause gastrointestinal bleeding.

It is clear that high-dose paracetamol ultimately not only offers little in terms of efficacy but, at least at high dose, may have an unfavourable therapeutic to toxic index—this does not take into account the potential liver toxicity that might attend at higher dose use.

Implications for Practice

While intermittent paracetamol to relieve occasional pain is safe and marginally may be high-dose effective, paracetamol should probably be avoided given its limited efficacy and risk of toxicity. If occasional paracetamol is not effective, intermittent non-steroidal antiinflammatory drugs or other pharmacological treatments should be considered. Furthermore, for osteoarthritis, exercise treatment has been shown to be efficacious, is safe and is underutilised.

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Polio Oz News

Which Fruits and Veggies Best Prevent Weight Gain?

By Veronica Hackethal, MD

Source: Medscape Medical News -29 January 2016

Eating more foods high in certain flavonoids may help prevent weight gain over time for adults, according to findings from a study <u>published</u> <u>online</u> January 27 in the *BMJ*.

"We looked at seven different types of flavonoids, and we found that the classes that were associated with better weight maintenance were flavonol, anthocyanins, and flavonoid polymers", commented first author Monica Bertoia, MPH, PhD, research associate at the Harvard TH Chan School of Public Health, Boston, Massachusetts.

Fruits like apples, pears, and red berries represent the major sources of flavonoids, but they can also be found in some vegetables like red peppers, Dr Bertoia said.

Preventing a Bit of Weight Gain Is Important for Health

The study is the first to look at links between intake of various flavonoid subclasses and weight gain. It included data on over 124,000 women and men in the United States who were followed for up to 24 years.

Past studies have suggested that flavonoids may play a role in weight loss. Most have focused on the flavon-3-ol subclass found in green tea, though, and have had small sample sizes.

The new study drew on data from 124,086 women and men who participated in three prospective studies: the <u>Nurses' Health Study</u> (NHS), <u>Nurses' Health Study II</u> (NHSII), and the <u>Health Professionals Follow-up Study</u> (HPFS).

Participants were aged 27 to 65 and came from all 50 states of the United States; they selfreported their weight, lifestyle habits, and recent medical diagnoses every 2 years between 1986 and 2011. They also documented their diet every 4 years using validated semiquantitative food frequency questionnaires (FFQs).

Researchers looked at seven flavonoid subclasses: flavanones, anthocyanins, flavan-3ols, proanthocyanidins, flavonoid polymers, flavonols, and flavones.

They adjusted the results for lifestyle factors linked to weight change, including physical activity, TV watching, and 17 dietary factors such as intake of sugar-sweetened drinks, fried foods, alcohol, caffeine, whole grains, and processed meats.

Results showed that over each 4-year period, women gained an average of 2.9 pounds (NHS)



to 4.4 pounds (NHSII), and men gained an average of 2.2 pounds (HPFS).

Though small, even this amount of weight gain "will really add up over the long term", Dr Bertoia pointed out.

"Preventing just small amounts of weight gain or losing small amounts of weight can have an impact on your individual health and risk of cardiovascular disease, diabetes, and cancer", she said, adding, "It can also have a really big impact on population health."

Which Fruits and Vegetables to Target to Prevent Weight Gain

The findings — adjusted for lifestyle factors — suggested that people who ate more foods from specific flavonoid subclasses experienced less weight gain over time.

The following flavonoids had the greatest effect on weight loss: anthocyanins produced -0.23lbs per additional standard deviation (SD)/day, flavonoid polymers -0.18 lbs per additional SD/ day, and flavonols -0.16 lbs per additional SD/ day.

Each increase in standard deviation of daily intake was linked to 0.16 to 0.23 fewer pounds (equivalent to 0.07-0.10 kg) gained over 4 years.

After fiber intake was accounted for, the findings remained significant for anthocyanins, proanthocyanidins, and total flavonoid polymers but lost significance for the other subclasses.

One serving per day of many fruits often provides many more flavonoids than one standard deviation, which may put these findings into perspective. For example, eating just a half cup of blueberries per day would increase consumption of anthocyanins by 12 standard deviations.

Foods high in anthocyanins include dark red fruits like blackberries, red grapes, raspberries, cherries, blueberries, and strawberries, with the

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Which Fruits and Veggies Best (cont'd from p15)

latter two fruits also high in flavonoid polymers, as are tea, pecans, and apples. Tea is also rich in flavonols, along with onions and some types of beans, Dr Bertoia pointed out.

The observational nature of the study limits conclusions about whether or not the findings are related to overall improvement in diet quality, to the flavonoids themselves, or to something else, according to Dr Bertoia. Other limitations include the use of a self-reported FFQ.

Nevertheless, this paper builds on prior research by this group and *"helps to refine the general advice that everyone should eat more fruits and* vegetables. It helps give more information about which potential fruits and vegetables may be better choices to make more specific recommendations in future guidelines", Dr Bertoia said

In the United States currently, most people consume less than 1 cup of fruits, and less than 2 cups of vegetables daily. The authors suggest that this should be increased to 2 cups of fruits and 2.5 cups of vegetables.

BMJ. Published online January 27 2016. Article.

WHO Calls For Major Shift Toward Older People

By Miriam E. Tucker

Source: Medscape Medical News -1 October 2015

A new report from the World Health Organization (WHO) calls for a dramatic shift in the way governments, societies, and health systems think about and approach a rapidly growing older population.

Timed to coincide with the WHO International Day of Older Persons on October 1, the organization's <u>World Report on Ageing and Health</u> was released September 30, 2015, at a briefing held at the United Nations Foundation headquarters.

By 2050, the number of people who will be older than 60 years is set to double. "Today, for the first time in history, most people can expect to live into their 60s and beyond. The consequences for health, health systems, for the work force, and for the budgets of countries are profound", WHO Director-General Margaret Chan, MD, said at the briefing.

The new report, she said, "summarizes the opportunities that accompany population aging, and also the many barriers and knowledge gaps that block these opportunities. It is in our collective interest to work together to unblock these barriers".

Among the current impediments are a one-sizefits-all approach to older people despite their great diversity and the notion that older age always implies dependence and increased cost. "There's a lot of misconception [that] chronological age is linked to functional disability. That's not the case", Dr Chan said.

John Beard, MD, director of the WHO's Department of Ageing and Life Course and a lead author of the report, told *Medscape Medical News*



that one of the report's implications for healthcare professionals is "to step beyond the idea that healthy aging is the absence of disease and to realize that what's more important for an older person is their functional ability that comprises both themselves and the environment they live in".

Older people should be viewed holistically, Dr Beard said. "Try and do some form of assessment as to how they're functioning and how all their different problems and challenges add up, and use that as a guide to [future action]", he advised, adding, "Unfortunately, systems at the moment often tend to react to seeing older people as a bucket of individual diseases and respond to each disease as the presentation arises. I think the first thing we need to do is to move beyond that, to think in a holistic way".

Think "Investment" Rather Than "Cost"

The 245-page report defines "healthy aging" as "the process of developing and maintaining the functional ability that enables well-being in older age".

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Major Shift Toward Older People (cont'd from p16)

To achieve that goal, detailed recommendations are provided for four "priority areas for action": Aligning health systems to the populations they now serve, developing improved systems of longterm care, creating age-friendly environments, and improving measurement and monitoring to ensure that the changes are having the intended beneficial effect.

The overall tone of the report is positive, asking that expenditures on older populations be viewed as *"investments"* rather than *"costs"*. It notes that population aging may not be that expensive, as has been assumed, in part because aging per se has been shown to contribute far less to overall healthcare expenditures than have changes in healthcare-related technologies.

And in fact, the report says that in some highincome countries, healthcare expenditures per person fall significantly after the age of 75, whereas expenditures for long-term care rise.

Nanopatch Polio Vaccine Success

by Darius Koreis

Source: <u>medicalxpress.com/</u> -26 February 2016

Needle-free Nanopatch technology developed at The University of Queensland has been used to successfully deliver an inactivated poliovirus vaccine.



The UQ research team - Ms Christiana Agyei, Dr David Muller, Professor Mark Kendall, Dr Germain Fernando and Mr Nick Owens.

Delivery of a polio vaccine with the Nanopatch was demonstrated by UQ's Professor Mark Kendall and his research team at UQ's Australian Institute for Bioengineering and Nanotechnology, in collaboration with the World Health Organisation, the US Centres for Disease Control and Prevention, and vaccine technology company Vaxxas. Dr Beard said that increases in healthcare costs with age tend to be higher in the United States than in some other countries, such as the Netherlands, Japan, Korea, and Germany, where there are comprehensive systems for long-term care.

"I hope this report gets people to realize that older populations are a fantastic opportunity.... The shift from just seeing older populations as a burden on society I hope will be one major step. And then, looking to how we can across the life course do things to ensure that the well-being and the contribution of older people are maintained for as long as possible".

He added, "That might cost a little bit — I don't think it will be nearly as costly as people think — but it's a good investment. And when you make a good investment, you get a return, in terms of the well-being of older people, their contribution to society, and social cohesion".

Professor Kendall said the Nanopatch had been used to administer an inactivated Type 2 poliovirus vaccine in a rat model.

"We compared the Nanopatch to the traditional needle and syringe, and found that there is about a 40-fold improvement in delivered dosesparing", Professor Kendall said.

"This means about 40 times less polio vaccine was needed in Nanopatch delivery to generate a functional immune response as the needle and syringe.

"To our knowledge, this is the highest level of dose-sparing observed for an inactivated polio vaccine in rats achieved by any type of delivery technology, so this is a key breakthrough".

The next step will be clinical testing.

Dr David Muller, first author of the research published in *Scientific Reports*, said the work demonstrated a key advantage of the Nanopatch.

"The Nanopatch targets the abundant immune cell populations in the skin's outer layers; rather than muscle, resulting in a more efficient vaccine delivery system", he said.

Clinical success and widespread use of the Nanopatch against polio could help in the current campaign to eradicate polio. It could be produced and distributed at a cheaper cost, and its ease of use would make it suitable for houseto-house vaccination efforts in endemic areas with only minimal training required.

Nanopatch Polio Vaccine Success (cont'd from p17)

World Health Organisation Global Polio Eradication Initiative Director Mr Michel Zaffran said only Afghanistan and Pakistan remained polio-endemic, but all countries were at risk until the disease was eradicated everywhere.

"Needle-free microneedle patches such as the Nanopatch offer great promise for reaching more children with <u>polio vaccine</u> as well as other antigens such as <u>measles vaccine</u>, particularly in hard-to-reach areas or areas with inadequate healthcare infrastructure", Mr Zaffran said.

Nanopatch technology is being commercialised by Vaxxas Pty Ltd, which has scaled the Nanopatch from use in small models to prototypes for human use.

Vaxxas CEO Mr David Hoey said the first human vaccination studies are scheduled for this year.

"Key attributes of the Nanopatch, including its ease of use and potential to not require refrigeration, could improve the reach and efficiency of vaccination campaigns in difficult-toreach locations, including those where polio remains endemic", Mr Hoey said.

More information: David A. Muller et al. Inactivated poliovirus type 2 vaccine delivered to rat skin via high density microprojection array elicits potent neutralising antibody responses, *Scientific Reports* (2016). DOI: 10.1038/srep22094

Journal reference: Scientific Reports

Provided by: University of Queensland

WHO's New Director of Polio Eradication

Source: <u>Rotary International</u> -21 January 2016



February, **Michel** Zaffran (pictured) will take over as polio director of eradication for the World Health *(WHO).* Organization Most recently, Zaffran served has as coordinator of WHO's Expanded Programme on Immunization. He has also served as Deputy Executive

Secretary of the Global Alliance for Vaccines and Immunizations (GAVI), and represented WHO on the working group that designed and launched GAVI. We caught up with him recently to ask his thoughts about this new challenge:

I am extremely excited, but also emotionally very moved, to have been selected for this position. I started working for the World Health Organization in September of 1987 in the immunization program. A few months later in May the World Health Assembly endorsed the resolution to actually eradicate polio. I was just at a very junior level but remember seeing my bosses work on the resolution, and so I was there from the very beginning. So to actually toward the end of my career be coming back and heading the program for its last miles basically is very exciting and very moving.

My past experience has prepared me very well for this role. I have been working with all of the

key partners for many years. And as the WHO's director of polio eradication, I will need to interact closely with the various stakeholders and ensure their contributions remain well coordinated.

Over the past three years, specifically as part of the Polio Eradication End Game Strategic Plan, I was the chair of the Immunization Systems Management Group responsible for coordinating the efforts of partners to prepare for the withdrawal of type 2 oral polio vaccine (OPV) from 155 countries and for the introduction of the inactivated polio vaccine (IPV) into 126 countries. All of this work has been done very closely with Rotary, with the Center for Disease Control and Prevention (CDC), the Gates Foundation, and UNICEF.

We have celebrated some very good milestones recently, but now is not the time to give up.

So let me talk a little about this important step. As you know, the OPV is a very efficient and very effective vaccine. But in some rare cases, it can actually cause the disease from the attenuated (weakened) live virus it contains. It can even return to being virulent, circulate, and cause outbreaks.

There are three strains of the polio virus. Last year, the Polio Eradication Global Certification Committee certified that no natural cases of type 2 have occurred since 1999 and that the virus had been eradicated. From a public health perspective, it is no longer acceptable to be causing the disease with the weakened form of type 2 when it no longer exists in nature. So during a two week period at the end of April, all countries that are currently using OPV either in

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New Director of Polio Eradication (cont'd from p18)

routine programs or in campaigns — there are 155 such places — will switch from the trivalent OPV (which contains weakened forms of all three types) to a bivalent OPV (which only contains types 1 and 3).

At the same time, we are introducing the injectable inactivated polio virus vaccine (IPV), which contains all three types of the virus in a killed form, into routine immunization systems. This will ensure that people continue to have protection and immunity against type 2 in case an outbreak were to occur, either from vaccine not entirely removed or because of an accident at a laboratory or manufacturer.

What remains to be done

We have celebrated some very good milestones recently, but now is not the time to give up. The fact that we declared Nigeria no longer endemic, that cases are just restricted to Pakistan and Afghanistan, sends a signal — which of course is a very good signal - of positive results. But at the same time there is a danger it can obscure the fact that we need to continue for a period of time to have very good surveillance in Africa and continue immunizing children. There are countries in Africa that are at risk, should anything happen, like we have seen in the past where the virus is imported from endemic countries.

Rotarians who have been so engaged and active in helping the program so far cannot let go. They need to continue to support the program and not only in Pakistan and Afghanistan, but in Africa where we need to ensure that there are the right campaigns conducted with high quality. What Rotarians should do is to continue to advocate that the job is not done yet.

(Rotary) had the vision as early as 1979 that this should be done and you convinced the rest of the world to move ahead and do it.

When we stop transmission in Pakistan and Afghanistan, and even after we have certification of global eradication, we will need to maintain high quality surveillance to ensure the virus is contained and not released into the environment.

And we need to make an effort — and Rotarians can contribute to this substantially — that the lessons learned through the polio eradication initiative, that the laboratories that we have established, that the skills that we have developed, that the staff we have trained, are not lost to public health. But that they are transitioned to new public health challenges. This is the fantastic broader legacy of the program.

I would like to recognize the unique role that Rotary and Rotarians have played in this fantastic adventure. You had the vision as early as 1979 that this should be done and you convinced the rest of the world to move ahead and do it. You have been there at the very beginning; you have been there all along. Don't give up now, we are so close, we've got the end in sight.

Scientists Advocate Need For New, Safer Vaccines

By <u>Ed Cara</u>

Source: <u>medicaldaily.com</u>—31 December 2015

Scientists Advocate Need For New, Safer Polio Vaccines To Prevent Outbreaks After Its Eradication

The end of polio looms ever, if precariously, <u>closer</u>. But what will happen to its vaccine afterward? That's the broad question broached by a group of researchers, led by Dr. Phillip Minor of the UK's National Institute for Biological Standards and Control (NIBSC), this Thursday in <u>PLOS Pathogens</u>.

As they explain, the global health community is poised to remove the oral polio vaccine (OPV) off the market permanently once eradication is confirmed — in hopes of preventing the rare possibility of an outbreak emerging from the weakened but very much live strain of the poliovirus utilized in them. Because the OPV has been the primary tool in polio prevention, however, the world will need a standby vaccine to maintain immunity for the foreseeable future. And while the current leading strategy is to jumpstart mass-production of the inactivated polio vaccine (<u>IPV</u>), using either wild-type poliovirus or the weakened "Sabin" strain as its base, Minor and his colleagues strongly believe a third option should be chosen.

While the IPV is one of the safest vaccines around, incapable of inadvertently causing polio or triggering the rare side effect of paralysis associated with the OPV, there are drawbacks involved in its production — namely, that most IPV manufacturers use batches of wild-type poliovirus to make them. While these batches are safely killed off long before they reach a syringe, the possibility of a factory leak into a populated area is still present, if unlikely. The risk is so feared that the World Health Organization (WHO), through its 2015 <u>Global</u> <u>Action Plan</u> for polio eradication, recommended

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Need For New, Safer Vaccines (cont'd from p19)

that no factories producing the wild-type version of IPV be built in low-income countries where a polio outbreak could be transmitted easily.

An IPV version using the Sabin strains of polio, the same type found in the OPV, carries a similar, if smaller, risk of contamination — should the Sabin strain be let loose into the environment, there's the remote chance it can revert back into an infectious, disease-transmitting version and ignite a new outbreak.

To get around these potential dangers, Minor and his colleagues sought to create an alternative version of the Sabin strain, one less susceptible to mutation, by modifying its viral RNA. They then took their new creation through its paces, testing not only its genetic stability, but whether they could adequately match up to the competition in terms of effectiveness, paralysis risk, and cultivability. "We have developed new strains for IPV production with negligible risk to the human population should they escape," they concluded.

Noting that the WHO's <u>Global Action Plan</u> calls for the formulation of an expert panel to evaluate the safety of new "derivatives containing wild poliovirus capsid sequences" by comparing them to the Sabin strain in the wake of posteradication, Minor and his team are hopeful their creation will fit that criteria.

Even should that happen, though, there are still stumbling blocks. According to a 2009 report from the Bill & Melinda Gates Foundation on the global IPV market post-eradication, the major manufacturers of the IPV have been adamant about their refusal to switch from using wildtype polioviruses to even the Sabin strain, citing their version's "proven track record of successful use." And while Minor's strain could be very useful in lower income countries that selfproduce their polio vaccine, there's the question of whether it could be ready for production by the time post-eradication efforts begin to ramp up - provided it actually works. Not to be forgotten in all this are the higher costs and overall lower protection that come with any version of the IPV compared to the OPV, though research efforts are underway to solve these problems.

Still, the drive to create a safer polio vaccine is one worthy of encouragement. Here's hoping it succeeds.

Source: Minor P, et al. PLOS Pathogens. 2015.

We're So Close To Eradicating Polio!

by Jesslyn Shields

Source: <u>How Stuff Works</u> – 18 February 2016

We're So Close to Eradicating Polio! Here's Why The Last Few Hurdles Are Tricky.

Have you noticed that nobody you know has come down with polio recently? That's great for you *and* everybody you know! It hasn't always been the case, and it also wasn't an accident.

Epidemics of <u>polio</u>, or poliomyelitis, have plagued human populations since before we started writing stuff like that down. The virus can be spread through the consumption of unsanitary food or water, or by any of the classic poopgetting-in-mouth scenarios you can think of. It most commonly infects children. Though not often fatal, polio can make its way into the brain and spinal cord, causing permanent paralysis.

Polio was a terrifying threat in the early 20th century: It often left victims paralyzed or dead. Yet two vaccines caused an immediate drop in polio cases and today they've nearly eradicated the disease. But what exactly happened? Tune in to find out.



Thanks to the polio vaccine developed by Jonas Salk in the 1950's, in conjunction with extremely and well-organized vaccination aggressive campaigns, the last case of polio caused by the "wild," unmutated virus was reported in the United States in 1979. In 1988, polio was reported to have a firm foothold in 125 countries worldwide, infecting around 350,000 people. Since then, Europe was certified polio-free in 2002, and the last case of polio in Africa was reported in Nigeria in 2014. The remaining 72 individuals with the wild poliovirus live in Afghanistan and Pakistan.

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So Close To Eradicating Polio! (cont'd from p20)

According to a <u>recent article</u> published in the New England Journal of Medicine, in order to completely eradicate polio, and to ensure that the virus doesn't come back in a mutated form elsewhere, we're going to have to start using a different <u>vaccine</u>.

Because there's not just one strain of polio there are three. All three of the viruses are contained in the vaccine we've been using all these years, but one of the strains - they call it type 2 - was eradicated back in 1999. The danger in continuing to use type 2 in the current vaccine is that it's possible, though rare, for the type 2 virus in the vaccine to give someone symptomatic polio, or vaccine-associated paralytic polio (VAPP). Even more alarming, but also more uncommon, is that the vaccine can infect someone with a mutated version of the type 2 poliovirus that is able to spread within a community in the form of circulating vaccinederived polioviruses (cVDPVs). Which is singularly unhelpful if one's goal is eradicating polio.

The numbers of people infected with VAPP or cVDPVs is small — on the order of around 1600-3200 and 600 victims, respectively. However, it's much larger than the number of wild cases still in circulation. It turns out, once a strain of a virus is eradicated, it's very important to stop using it in the vaccine, to avoid situations like cVDPVs. So the next order of business is switching vaccines from the trivalent vaccine that contains all three strains of poliovirus, to the bivalent vaccine that contains only type 1 and type 3. This sounds easy, but it's not actually going to be all that easy.

"This is unprecedented", says Walter Orenstein, associate director of the <u>Emory Vaccine Center</u> and co-author of the recent article, via email. "The big concern with the switch deals with the need to do it simultaneously, within a two week period.

As it happens, vaccinating a population has to be a highly orchestrated affair: in high-risk countries where polio was eradicated fairly recently, the transition from the trivalent to bivalent vaccine needs to begin with every child getting the trivalent inactivated polio vaccine (IPV) for a little while longer, until there are no more reported cases of VAPP.

After that, every single country that has been using the trivalent vaccine has to destroy or safely contain them all at once, at which point they have to begin stockpiling and administering the bivalent vaccine.

The reason to stop in this coordinated fashion is if some countries continued to use type 2 containing oral vaccines, whereas others stopped using such vaccines, then the countries which have stopped could be at risk of getting seeded with type 2 vaccine viruses from the other countries. This could lead to generation of more cVDPV2s", says Orenstein.

In order for this switch to run smoothly, global health organizations, governments, vaccine manufacturers, and funders have to work together to make sure type 2 polio is contained, while preparing for another outbreak, just in case.

No Injectable Vaccine On The Market

Source: <u>Times of India</u>—2 March 2016

Lucknow: Acute shortage of injectable polio vaccine in the private sector is bothering paediatricians and urban parents in Uttar Pradesh. The crisis, believes All India Vaccine Dealers Association, has been triggered by bulk procurement by state government for the National Polio Immunisation Programme.

According to general secretary Sanjiv Pal Singh, "Not a single vial of the injectable polio vaccine is available against demand for at least 30,000 vials as companies have diverted supply to state government".

In November 2015, UP government integrated injectable polio vaccine in the national programme for elimination of polio. Under this, polio vaccine shots are given to newborn when they complete 14 weeks.

Principal secretary health Arvind Kumar said: "We had no idea about the shortage or crisis. Now informed, we will urge parents to go to government hospitals which have enough stock. Additionally, government will meet representatives of the vaccine manufacturing companies soon to address the issue".

Privately practising paediatrician Dr Sanjay Niranjan who has an average of administering some 50-60 injections every month said, "Our stockist informed that he has zero stock". Adding that many parents get worried and fear compromising with the oral polio vaccine.

"Injectable polio vaccine gives better protection. It is for this that global alliance for vaccine and immunisation recommends it", he said. The association office-bearers held that the crisis was equally grave in Kanpur, Ghaziabad, Noida, Varanasi and Gorakhpur.

Members of the Indian Paediatric Association have expressed concern stating that over 60% of urban children are immunised in the private sector and injectable polio vaccine was one important element.

The Tale Of The Pakistani Taliban Father

By Jeffrey Kluger

Source: <u>Time.com</u>—15 January 2016

Even though the Quetta attack showed the Taliban is still bent on disrupting Pakistan's attempts to eradicate polio, a one-on-one encounter proves instructive.

There's a special place in hell for the suicide bomber who <u>killed 16 people</u> at a polio vaccination center in Quetta, Pakistan on Jan. 13. There's a place too for the Pakistani Taliban spokesman who claimed credit for the attack—as well as for his whole blood-soaked organization.

The Taliban have been targeting polio workers for <u>several years now</u>, insisting that no children can be vaccinated until U.S. drone strikes in the country stop. They have also spread rumors that the vaccine contains HIV or is designed to sterilize Muslim girls, and that vaccinators are CIA spies in disguise — a fiction that gained currency after agents pulled <u>just that</u> <u>masquerade</u> while hunting for Osama bin Laden.

Still, after decades of work, victory might be at hand in the fight to eradicate polio. As recently as 1988, the disease was endemic in 125 countries and paralyzed or killed 350,000 children every year. By last year, polio was down to just two countries — Pakistan and Afghanistan — with a total of 70 cases between them.

Pakistan, which had 51 of those cases, is the center of the fight to bring the global case count down to zero. On Jan. 14, the country completed a National Immunization Day, distributing one dose of vaccine to each of the 35.5 million children under five in the country. A second dose will follow in March, and three regional immunization days in February, April and May aim to reach 5 million children each time. In all, 86 million doses of vaccine could be delivered and administered. Armed forces were dispatched year to contain the Taliban when last vaccinations are under way and imams have been enlisted to spread the word that the drops are safe and to remind parents that the Qur'an instructs them to safeguard the health of their children.

But if the campaign is going to succeed, hearts and minds in the tribal regions will also have to be changed. That's something Aziz Memon, a leading Pakistani textile manufacturer and a chairman of <u>Rotary International's campaign</u> to wipe out polio, knows something about. It is Rotary that got the global eradication movement started in 1988, and has done more than any other organization to see it through, raising and distributing \$1.5 billion to vaccination efforts over the years. In a recent conversation with TIME, Memon described an experience he had when he visited a hospital in Peshawar to drop off some wheelchairs and took a break to have tea and a biscuit. A hospital worker told him that a Taliban chief and his 18-month old son—who had been stricken with polio and lost the use of his legs were in a room nearby. This was the kind of man who could make a difference if he could be persuaded to support vaccinations. Memon went into the room to have his tea and chat with the man while the child played on the floor.

Eventually the topic of the boy's illness came up and Memon chose to tell the father a hard and candid truth. "*If you had given this baby two drops"*, he said, "*he'd be running now"*.

The man, who was wearing a gun on his hip, grew visibly angry. "*Are you God"*? he demanded. "*It was his destiny to suffer this way, and now you are challenging me"*.

Memon apologized for giving offense and the two fell silent. At length he noticed that the room had become overly hot and that the boy, who was wearing two sweaters, looked uncomfortable. He recommended that the father remove the sweaters but the father refused, saying that his family came from a cold, mountainous region where the boy was used to bundling up, and he didn't want him to get flu or pneumonia. Memon saw his moment.

"But wouldn't that be his destiny"? he asked. "Now I am challenging you".

The Taliban chief, hardly a sympathetic figure, nonetheless did what an ordinary father would do, which was to grow teary. "You said you could have given him two drops before", he said. "Could you give him four drops now"?

Memon nodded his head. "No", he said. "It's too late".

Nonetheless, Memon did extract a promise from the man: that he would take some vaccine with him when he left the hospital, vaccinate the rest of his family and offer the drops to his neighbors as well. The man promised he would, then asked Memon for his cellphone number, explaining that he would be sending him a message within the week, and when he got it, he was to read and delete it. Memon agreed. Six days later a text arrived saying that the man had fulfilled the promise he'd made. Memon, as he'd promised in return, erased the message from his phone.

There may never be a way to verify Memon's tale, but even if it is destined to become merely a part of polio apocrypha, its larger lesson is important. In a world of the bloody and bad, it may take only a single human exchange to produce bits of fragile good.