POLIO NSW *formerly Post-Polio Network (NSW)*

NETWORK NEWS

Incorporating – **Polio Oz News**

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Country Conference 2018

Panthers Port Macquarie

(www.portmacquarie.panthers.com.au)

1 Bay Street, Port Macquarie

Cost: $35.00

Informal Conference Dinner:
Friday, 21st September, 2018, 6.30pm

Conference Program:
Saturday, 22nd September 2018, 9am to 5pm

The Country Conference allows all Polio NSW members, their partners, family and friends, especially those from the Mid North Coast and surrounding areas, to find out about issues and services relevant to people with the Late Effects of Polio (LEoP). This Conference will be hosted by the Port Macquarie Support Group. Spring is a wonderful time to visit Port Macquarie (www.portmacquarieinfo.com.au) so why not make it a holiday - we look forward to seeing you there!

Speakers include:

- **Dr Roslyn Avery,** Rehabilitation Specialist at Port Macquarie Private Hospital and also in private practice at Port Macquarie and Foster.
- **Paul Cavendish,** Accredited Exercise Physiologist and Clinical Educator for Polio Australia. Paul is currently delivering workshops to health professionals on identifying the signs and symptoms of the LEoP.
- **Margaret Invernon** – *Keeping Fit as you age with a disability* – Margaret is an Accredited Exercise Physiologist. She works at a multidisciplinary Allied Health Professional Centre located in Armidale.
- **Julie Haraksin –** *Advocacy* – Julie is a trained Social Worker working in the disability field. She has held positions in the non-government sector as a community-based advocate, as a policy adviser and planner for TAFE NSW.
- **Linda Walters** – *Discussion Panelist* – Occupational Therapist. Linda has been working as a community Occupational Therapist since 2009 after completing a Bachelor of Applied Science in Occupational Therapy at Western Sydney University.
- **Don Scott** – *Discussion Panelist* – Podiatrist. Don has worked in Podiatry since 1984 and has had a practice on the south coast and north coast of NSW. He has been making orthotics since 1974. For the last 24 years he has been involved with medical grade footwear and has a partnership with Jonathan Herreen (Guangzhou China). They have developed a 3D scanning system and an integrated computer program that scans the foot and leg to make Footwear, Orthotics and AFO's.

Please return the enclosed Registration Form with your payment to the Polio NSW Office by Friday 14th September, 2018

Time Flies when you are having fun

Documented by Bryan Wishart in consultation with Vilas Mehabubani

Bryan has been a committed and generous supporter of Polio NSW since he first made contact with us in 1999. Although not a polio survivor himself, he has gone out of his way to help and encourage young polio survivors.

It is hard to believe that more than fourteen years have passed since I introduced Vilas Mehabubani in the December 2003 edition of *Network News*. That story finished with Vilas waiting for his visa so that he could make his first trip to Australia. A lot of water has passed under the bridge since then.

The visa approval came through in time for Vilas to travel to Sydney (with me) in time for Christmas 2003. This was Vilas' first time in an aeroplane. He was so excited. Once on board, he kept looking out of the window as we travelled to Singapore, amazed at what he could see. It was difficult to tear him away to eat dinner.

We changed planes in Singapore for the overnight flight to Sydney. As we prepared to land in Sydney, Vilas was so happy to see the Sydney Harbour Bridge and the Sydney Opera House. Just like what he saw in the calendar he had at home.

We packed a lot into Vilas' three month stay. Apart from enjoying the sights of Sydney, we drove to Albury and the Blue Mountains on separate trips.

Vilas returned to Sydney towards the end of 2004 to attend an English college in Bondi Junction so that he could improve his English as well as being able to meet other people. That worked out very well. His English improved markedly and he befriended people from Asia, Europe and South America.

Before he went home to Mumbai, we managed to fit in a visit to New Zealand. While we were in Queenstown, Vilas was over the moon to experience snow for the first time.

Having had a taste of life in Australia, we both agreed that Vilas ought to return to Sydney to further his education. Vilas was enrolled in a Diploma of Tourism course at the International College of Management, Sydney (ICMS) in Manly that ran from February 2007 until September 2008. He lived on campus, which gave him the opportunity to socialise with other students and make new friends, particularly from India, Norway and Sri Lanka.

With an appetite for education, Vilas decided to proceed onto the Bachelor stream at the same college, graduating in 2010.

Still in love with Sydney, Vilas wanted to find work in his city of dreams. Easier said than done. Then fate took hold. We approached ICMS to see if they had anything available. Great timing as they were creating a new position: Night Manager on Duty. With Vilas' experience as Night Receptionist, a role he had done for his 9 month Industry training, and as a part-time Night Auditor, the interviewer felt he had the right background and temperament for the role. As a result, Vilas was very pleased to get the job.

Vilas' student visa was about to run out in June and he needed to apply for a 457 work visa. So, he had to leave the country. It was thought that the 457 visa process would only take a couple of weeks. It was suggested that he go to New Zealand to wait. Fortunately, he decided to go home to Mumbai. The visa process dragged on for months before being approved in October 2010 in time for him to attend the graduation ceremony. Nothing is ever straightforward with Vilas!

Then, it was time to start work in October 2010. Vilas settled into the role and seemed to be doing a very good job. He got on very well with the students and was well respected by the staff. During the CEO's speech at one of the college's anniversary dinners, he singled Vilas out, heaping praise on him for the work he was doing. This did much for his confidence and self-esteem.

The next huge moment in the life of Vilas was getting married. The wedding to Eva took place on the 11th of December 2013 (11/12/13) in Mumbai, which I was fortunate to be able to attend. There was a lovely church service, followed by a reception. Much to the amusement of the gathering, I gave a speech at the reception in English that was translated by Eva's uncle into Marathi. Then the bride and groom welcomed a long line of guests armed with presents. This went on for hours. A few days later, they began their honeymoon in Goa, a state on the south western coast of India.

A couple of weeks later, another wedding, with Vilas' brother Vikas marrying Jayshree. Vilas returned the favour as best man.

In January 2014, Vilas returned to Sydney, with Eva following in May once her visa had been approved. The next wonderful occasion for the couple took place in April 2016, when Jonathan was born. Then a further major event with the Mehabubani family being granted Permanent Residency status in January 2017.

A lot of water has certainly passed under the bridge over the 16 years since I first communicated with Vilas. So, something that started out as a short-term desire to encourage someone in India with polio to lead a more fulfilled life has developed into a very interesting and exciting journey.

Vilas must be congratulated on how he has developed and achieved success, combatting the challenges that he has faced in life.

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Ask Dr Maynard

Send your questions for Dr. Maynard to info@post-polio.org
See other questions at www.post-polio.org/edu/askdrmay.html

Question: *I was recently diagnosed with cancer. My oncologist has recommended chemotherapy. Are there any specific concerns polio survivors should have regarding chemotherapy that my oncologist might not be aware of? How will it affect my post-polio weakened muscles? Are there specific side-effects that tend to be more severe among patients with a prior history of polio? Is there anything I can do to mitigate this? What sort of pre-planning would be most helpful?*

Answer: There are several special concerns related to a polio survivor's undergoing cancer chemotherapy treatment (CCT). Firstly, please understand that your decision to agree to a recommendation for CCT will always involve the weighing of risks versus benefits of the treatment. Thus, your first issue will be gaining an understanding of the likelihood that the CCT will be curative, possibly curative (what are the odds of cure?), or strictly palliative (that is, living longer—what are the odds and for how long?). The answers to this issue will affect your balance of weighing risks and benefits.

The first special issue for polio survivors (PSs) to consider is the short-term expected side-effects of the specific chemotherapeutic agent(s), or drug(s), being recommended. Many, but not all, CCT drugs are given by IV infusion and leave even able-bodied people very weak and exhausted for approximately one to three days after receiving them. For PSs with PPS-related weakness and fatigue and/or precarious safe independent functioning in walking and ADLs (activities of daily living), they may need to plan on considerable amounts of additional assistance for routine daily activities after receiving CCT because they will likely have exaggerated and/or prolonged short-term debilitation (i.e., being “completely wiped out”). This side-effect may pose serious and unique challenges for PSs with significantly compromised ventilatory capacity. These problems are usually worth planning to ensure if the CCT is expected to be curative. In other circumstances the severity of this problem may alter the risk-benefit equation; and a decision to “try CCT” can be reconsidered after experiencing for yourself what happens after the first course or dose of the CCT.

The second special issue for PSs to consider is: Do any of the specific chemotherapeutic agents recommended in a course of CCT have any known “neurotoxic side-effects.” Peripheral neuropathy is the most common of these. If they do (and many do), these side-effects are more likely to occur or be worse among PSs because they already have vulnerable and often overworked motor nerve cells. In my experience, the later slow development of increased weakness and fatigue, sometimes with distal sensory loss, is more common among PSs a year or two after a course of CCT involving known neurotoxic agents. With some neurotoxic drugs, dietary changes and/or specific vitamin supplementation can sometimes reduce these risks and should be tried. With some agents a reduced or minimum dose may be worth considering, since it is likely these side-effects are dose dependent.

In summary, pre-planning for special needs is important for PSs undergoing CCT. Maintaining as much physical activity and exercise as possible during and after a course of CCT is recommended, with professional assistance of rehabilitation professionals as indicated. Thoughtful individual consideration of both short-term and long-term risks and benefits is encouraged.

Post-Polio Health Vol. 33, No. 4 Fall 2017 <www.post-polio.org>

Ask Dr Maynard

Question: *About a year ago, I was diagnosed with Parkinson’s Disease (PD). Then recently, when providing medical history to a new eye doctor and reporting that I had polio as a child, I learned from him that he and a colleague authored a letter which was published in* NEJM (New England Journal of Medicine) *about polio and PD. My father also had PD. I learned from the medical record of my hospital admission for polio that the doctor documented my father had polio as a child with some residual in a leg. (I remember his misshapen foot and atrophied leg.) Although Dr. Raymond Roos at the University of Chicago Post-Polio Clinic did not diagnose PPS, I believe that I definitely have some of the late effects. Some of the PD symptoms are similar, as you may know. I am interested to know what experiences you may have had with others who have had a polio history and now PD. Is there a connection? There can’t be many folks who fit into the category.*

Answer: There have been many cases of adults with a history of childhood polio developing PD. One of the first reports of this is in a 1978 *NEJM* article[1] and may have been co-authored by the eye doctor you met! A relationship has long been observed between PD and a history of previous encephalitis due to several different types of viruses that may cause damage to the brain, particularly to the substantia nigra (SN) which is a small area of the brainstem that develops a deficiency of dopamine production in patients with PD and is thought responsible for most PD symptoms. Bodian documented polio virus damage to the SN in autopsy cases during the 1940s[2]. More recently an MRI study on a child with acute wild polio in India documented changes in the SN.[3] Therefore, it is certainly plausible that previous polio virus-caused encephalomyelitis can affect the SN and predispose it to later-life degenerative dysfunction resulting in PD. A 2010 epidemiologic report from Denmark actually documented a 2.3 times higher risk of developing PD among people with a history of polio compared to controls matched for age, gender and geographic location.[3]

In light of these facts from the medical literature review of PD and polio that your question initiated, I think it is likely more than coincidental that you and your father both developed PD many years after having had childhood polio. I have personally seen a handful of patients with your two diagnoses, and I don't recall any unusual problems they shared in common. Both conditions can benefit from individualized exercise programs to slow down symptom progression and from rehabilitation strategies to preserve and/or enhance functional capacities.

1. Vincent FM, Myers WG. Poliomyelitis and Parkinsonism. *N Engl J Med.*1978;298:688-689.
2. Bodian D. Histopathologic basis of clinical findings in poliomyelitis. *Am J Med.*1949;6:563-577.
3. Nielsen NM, Rostgaard K et al. *JAMA.* 2002;287:1650-1651

Post-Polio Health Vol. 34, No. 2, p2, Spring 2018 <www.post-polio.org>

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www.polioplace.org

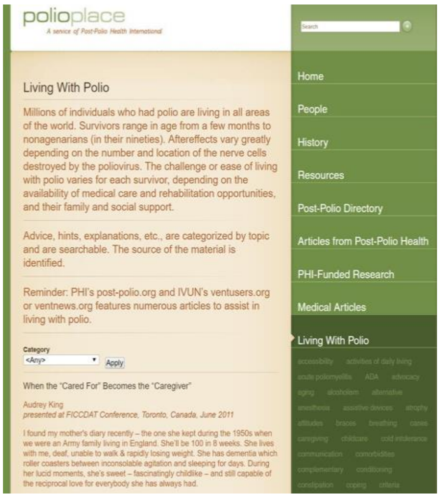
Polio Place: information and advice you can use

In 2011, with the help of a generous grant from the Roosevelt Warm Springs Foundation, PHI (Post-Polio Health International) launched Polio Place (www.polioplace.org). It was intended to serve as a dynamic internet repository for medical and practical information, historical records and artifacts. A major component of Polio Place was focused on examining the past.

The "People" section catalogued the history of the disease by examining not only those involved in the effort to develop a vaccine (those such as Leone Farrell, Jonas Salk and Albert Sabin), but also those who aided in rehabilitation efforts for survivors (such as Sister Kenny, John Affeldt and Jacquelin Perry).

The "Artifacts" section focused on the history of the disease, as well, but through the eyes of its survivors. PHI asked survivors to submit short narratives to help expand the understanding of equipment, family life and rehabilitation, and offer insight into their experiences through letters, old photos, medical records and newspaper articles. We encourage those who still wish to do so, to visit this section and submit their own "artifact".

One often overlooked aspect of Polio Place, though, is its wealth of resources intended to help those now dealing with the challenges of living with the late effects of polio. The aptly-named "Living With Polio" section contains numerous entries – organized by topic in a blog-style



Living With Polio

Millions of individuals who had polio are living in all areas of the world. Survivors range in age from a few months to nonagenarians (in their nineties). Aftereffects vary greatly depending on the number and location of the nerve cells destroyed by the poliovirus. The challenge or ease of living with polio varies for each survivor, depending on the availability of medical care and rehabilitation opportunities, and their family and social support.

Advice, hints, explanations, etc., are categorized by topic and are searchable. The source of the material is identified.

Reminder: PHI's post-polio.org and IVUN's ventusers.org or ventnews.org features numerous articles to assist in living with polio.

When the "Cared For" Becomes the "Caregiver"

Audrey King
presented at FICCDAT Conference, Toronto, Canada, June 2011

I found my mother's diary recently – the one she kept during the 1950s when we were an Army family living in England. She'll be 100 in 8 weeks. She lives with me, deaf, unable to walk & rapidly losing weight. She has dementia which roller coasters between inconsolable agitation and sleeping for days. During her lucid moments, she's sweet – fascinatingly childlike – and still capable of the reciprocal love for everybody she has always had.

format – intended to provide in-depth information or advice on subjects relevant to polio survivors today. We are continually updating and adding new material to this section. In addition, a number of video presentations on various topics can be found in the section “Post-Polio Experts Present.”

Articles from Post-Polio Health

Past Issues of *Post-Polio Health*©
Listed by Topic

Post-Polio Health, known as *Polio Network News* prior to 2003, is the quarterly publication of Post-Polio Health International. Complete issues can be found on PHI's Collection page.

Published in February, May, August and November.
Edited by Joan L. Headley, editor@post-polio.org.

Topics

Aging with Polio | Ask Dr. Maynard | Assistive Technology | Breathing/Swallowing | Clinics/Physicians | Education/Training | End of Life | Eradication | Exercise/Activity | History | Independent Living | Management/Coping | Management/Treatment | Medication | Nutrition | Pathology/Cause | Polio and Other Illnesses (co-morbidities) | Polio Survivors in Developing Countries | Promoting Positive Solutions | Relationships | Research | Support Groups | Surgery | Travel | Universal Design/Accessibility | US Government | Vaccines | Women

Aging with Polio

A Tribute to My Mother, Viola Filler (Vol. 33, No. 3)

Aging in place with a Disability (Vol. 31, No. 4)

Let's Clink Our Champagne Glasses! (Vol. 30, No. 4)

Celia Yoder Looks Toward 99th Birthday (Vol. 30, No. 2)

Aging Well with Post-Polio Syndrome: The Weight of the Matter (Vol. 28, No. 4)

Recently we added a section, “Articles from Post-Polio Health”, where one can find all previously-published articles from this newsletter arranged by topic. In the introductory paragraph, there is a link to PHI’s collections page, where one can find links to all past newsletters arranged chronologically, as well as a number of other non-PHI publications from our archives.

We also added a section, “PHI –Funded Research”, so that you can stay up-to-date on the latest research news from PHI. You can also easily stay abreast of new opportunities to participate in research from other institutions.

Finally, we added a menu tab for the Post-Polio Directory. We’ve received numerous comments in recent years from people who find <www.post-polio.org> difficult to navigate. Many particularly had trouble locating the directory on that site. In response, we decided to include a tab on the main menu on Polio Place to facilitate easy access to the directory.

As always, PHI invites you to participate in making Polio Place better. Submit an artifact. Send us your life story. Tell us about a particularly useful piece of adaptive equipment you own and include a picture. Let us know about a new book, video, website or article you’ve come across. We look forward to hearing from you!

Post-Polio Health Vol. 34, No. 2, p3, Spring 2018

The Power of Story

One Civilian’s Experience of Triumph Over Polio, the Fall of Saigon, and the Reinvention of Herself
Excerpt from *Standing Up After Saigon: The triumphant Story of Hope, Determination, and Reinvention.*

Shattered Dreams

Memories of April 1975 are seared into my brain like a branding iron stamped on the flesh of a cow. I remember the events vividly, as if they happened yesterday. My heart thunderously pounds in my chest as I share my story with you.

My new rattan suitcase with red leather trim sat in the corner of the living room. It was filled to the brim with hope of a new life.

Mom and I had spent several days shopping for new clothes for my trip to West Germany. She carefully packed each item with love and care. My favourite outfit was a big orange-and-white polka-dot shirt and pants. This colourful, cool pantsuit was the last item packed. Mom placed my travel documents on top of my mod-looking outfit. I was scheduled to leave Saigon on June 14, 1975.

I needed to be brave. I was five years old, and I was going to travel from Saigon to West Germany for polio rehabilitation therapy. My leg muscles had atrophied, and my left leg bent at an odd angle, like a broken pencil, as I crawled along the floor. My clothing had ragged holes in the knees from my aggressive movements to keep up with my older brother, Quang Phuong, my sister, Linh Phyong, and the neighbourhood kids.

If I could have looked at a map I would have seen that the Viet Cong had conquered all of the country north of Saigon. The Viet Cong were moving rapidly from the eastern Cambodian border into an area south of Saigon and north of Can Tho. The city of Saigon was being encircled by Communist troops.

We began hearing thunderous bombs and explosions along with the wailing of sirens in the early morning hours of April 29. I was petrified and frozen in my spot. I was not sure what to do, and Mom looked like a lost child. Our burly neighbor banged on our door, came running inside, and began digging a shelter under our kitchen floor, close to our front door. Mom and Uncle Dinh immediately began helping him dig.

Mom yelled to my brother Quang Phuong to break the legs off of one of our kitchen chairs. Our neighbour grabbed a hammer and nails and quickly constructed a crude ladder for our shelter. After several hours of digging, we had a hiding place that would hopefully keep us safe from bombs, mortar fire and enemy soldiers. Homemade shelters in Vietnam were called *hams*.

Uncle Dinh was the last person in the ham. He placed two large metal sheets over the top of the bunker. Once the ham was covered, the air became hot and sticky, and it felt like living inside a coffin. I felt like I was suffocating and couldn’t breathe, but I didn’t dare complain.

The noises outside were horrendous. There were deafening explosions that shook the ground like a never-ending earthquake. We heard artillery shells dropping on our rooftop, and it seemed like our home was going to crumble and bury us alive. Then it became eerily quiet and still. We were unsure if we should come out of the bunker. Each time we thought about venturing out of the ham, another rocket exploded nearby.

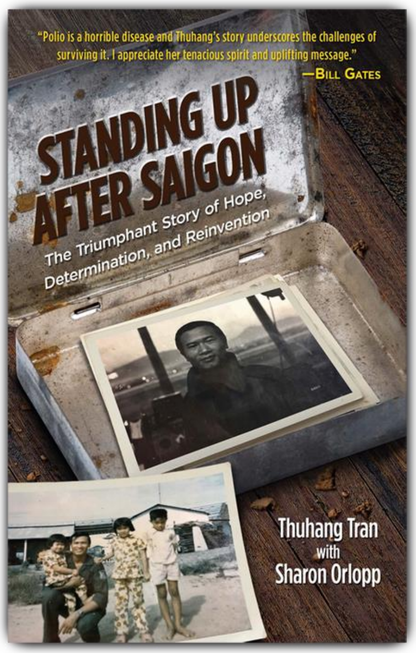
On the morning of April 30, we crawled out of the ham when we hadn’t heard any artillery chatter from the M-16s and AK-47s or any overhead screaming rockets for several hours. We quickly used the bathroom and began searching for scraps of food in the kitchen. We shared some dried instant noodles, a stale piece of bread, and a rotten guava.

Suddenly, our neighbor burst into our house carrying his Sony transistor radio. “*Hurry, President Minh is about to make an important announcement. Come over to my house to listen*.” As we walked outside, we gagged on the acrid smell of explosives. Our family quickly arrived next door and crowded into his home, which already had many neighbors, friends, and relatives packed inside.

At five years old, I didn’t understand what was being said on the radio until someone yelled, “*The war is over!*” Some people were crying, some were cheering, and others sat in stunned silence. The radio announcer described the chaotic scene in Saigon from the day before when last-minute helicopter evacuations occurred from the grounds of the US Embassy. Thousands of South Vietnamese had surrounded the wall of the embassy and were desperate to be one of the lucky ones chosen to fly to freedom.

The radio announcer’s voice went up several octaves as he announced that a Viet Cong tank had just smashed through the elaborately decorated steel gates of the Presidential Palace. A single soldier ran across the palace grounds carrying the flag of our enemy: crimson red on top and blue on the bottom with a bright yellow star in the middle. The flag was hoisted up and flown from the Presidential Palace. Then the streets of Saigon were flooded with Viet Cong tanks, trucks, and troops weary and intoxicated with victory.

As we walked back into our home, I noticed that the heart of my small rattan suitcase had been pierced by shrapnel. The guts of my dreams were strewn with clothing and rubbish on the floor. In the flash of an instant, our entire world had turned upside down on April 30, 1975.



Standing Up After Saigon: The Triumphant Story of Hope, Determination and Reinvention is the incredible memoir of Thuhang Tran as told by author Sharon Orlopp. With a scarcity of personal, civilian memoirs from Vietnam, this story provides a unique window into a particular area in history.

Born in Saigon near the end of the Vietnam War, Thuhang was two-and-a-half years old when she contracted polio, which left her legs partially paralyzed.

Orlopp recounts how Thuhang's parents and siblings cared for her and sacrificed to get her the treatment that would enable her to walk again. But their efforts were disrupted when communists invaded South Vietnam and her father, Chinh, an air traffic controller in the South Vietnam Air Force, was lost in evacuations and presumed dead.

The powerful memoir follows Thuhang and her father Chinh through their respective struggles, from Thuhang's battle with polio and the impact of her father's absence to Chinh's immigration to the United States and his desperate fifteen-year mission to be reunited with his family. Thuhang remained hopeful and resilient through all the seemingly impossible hurdles she's faced and lives today to tell her story and inspire those around her to find strength through perseverance.

Thuhang's journey is a gift of courage, hope, perseverance and family love. She wrote this memoir hoping to inspire those who "*feel invisible, under-appreciated, under-utilized, made fun of, disrespected and not valued. I hope my journey as a person who is an immigrant and differently abled will build bridges, encourage cultural understanding and give inspiration for treating all people with dignity, respect and inclusion*."

To learn more about Thuhang Tran's triumphant story, view the book trailer at <youtu.be/gEyGAWioSrI> or visit <www.StandingUpAfterSaigon.com>.

Standing Up After Saigon is available at Walmart.com, Amazon and Barnes and Noble.

Post-Polio Health Vol. 34, No. 2, pp6-7 Spring 2018

REMINDER: MT WILGA LEoP ASSESSMENT

For an assessment under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie, you will need to obtain a referral from your GP or other specialist. We encourage those that have already been assessed at the Clinic to return annually for follow up treatment. To make an appointment and to consider assessment options, or for more information, please contact Dr Mackie's office on **(02) 9847 5085**. You can fax your referral on **(02) 9847 5013**.

Where does the Assessment take place?
Mt Wilga Private Hospital is a specialist dedicated rehabilitation hospital and day therapy centre.

Mt Wilga
Private Hospital
Part of Ramsay Health Care

66 Rosamond Street
Hornsby NSW 2077
<www.mtwilgaprivate.com.au>

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CHF Consumers Health Forum OF Australia

Consumers Health Forum of Australia receives funding from the Australian Government as the peak national healthcare consumer organisation under the Health Peak and Advisory Bodies Programme

Codeine Storycards 2018

The Consumers Health Forum has commissioned the following resources to support your conversations with consumers about pain management.

- A set of six storycards using humorous line drawings and trigger questions/ statements.
- A set of key messages relevant to each illustration.
- A slide deck so you can include the materials in presentations and forums.
- This PDF printable document explains how to use the storycards and provides additional notes and links that you can use with both print out versions or slide deck materials so that you can enrich the conversation with evidence based comment and feel confident in responding to questions.
- PDF files for printing the storycards into postcards for distribution. The file named "Codeine-project-CARDS-DL.pdf" is the print file to provide to commercial printers for printing large quantities of the 6 kinds of DL size postcards (99 x 210mm).

The file named "Codeine-project-CARDS-A4.pdf" is for in-house printing and is formatted so that there is 2 sets of 3 cards (fronts and backs) to print out on A4 sheets.

Who can use the storycards?

The storycards and the supplementary notes can be used by health professionals, support groups or organisations, or between consumers, their friends and families. What do the storycards tell us? The storycards are an engaging visual prompt for positive conversations about pain management. The illustrations relate to everyday life and the challenges of pain management. The cards are specifically designed to help people move forward with their pain management and to find alternatives to over-the-counter medications that contain codeine.

They have been created as desirable objects that will be passed along and outlast most purely informational materials. Everyone will interpret the line drawings and the key messages in different ways. That's intentional. What a great way to start a conversation!

How do I use them?

- Use as a set or independently. Some messages may work better for your needs/your organisation than others. You may wish to add some additional information and other web links that relate to your profession or your support organisation/group.
- The aim of the storycards is to start a conversation. This might be face to face between health professionals and consumers, via Facebook, Instagram or Twitter, or between consumers, families and friends. Perhaps you have a story of your own that you would like to use to start the conversation alongside the cards.
- Print out the cards as postcards. Put them out wherever you might stop and chat with people – maybe some at your desk, at the front counter, in the surgery, on the coffee machine in the tea-room or on your fridge at home. In fact, take the cards everywhere you go!

- The postcards are often valued as a take-home gift, as part of a ‘sample bag’ or as freebies at events.
- Include the storycards in your presentations or as part of webinars and use the slide deck to showcase positive ways to work with consumers about pain management.
- Use the PDF version (with its additional information) into handouts to use for forums, groups or with individual consumers. Print out the PDF to use together with the slide deck – so you have additional information on hand.
- Use the illustrations and key messages to start the conversation on Facebook, Instagram or Twitter.

Read the media release about these cards here.

See the links below for “No more over-the-counter” storycards and supporting documentation:

- How to use the Consumers Health Forum Storycards <chf.org.au/sites/default/files/codeine-project-pdf.pdf>
- Storycards at A4 size <chf.org.au/sites/default/files/codeine-project-cards-a4.pdf>
- Storycards at DL size <chf.org.au/sites/default/files/codeine-project-cards-dl.pdf>
- Presentation Slides to inform others of the Storycards <chf.org.au/sites/default/files/codeine-project-slides.pdf>

Resources:
codeine-project-pdf.pdf (3.05 MB)
codeine-project-slides.pdf (3.6 MB)
codeine-project-cards-a4.pdf (3.39 MB)
codeine-project-cards-dl.pdf (3.54 MB)

CAUTION: False Positives in Polio Survivors with Post-Polio Sequelae Who Are Given Mental Status Examinations

INTERNATIONAL CENTRE FOR POLIO EDUCATION

By Dr. Richard L. Bruno, HD., PhD.
The Post-Polio Institute and The International Centre for Post-Polio Education
February, 2018

In our 37 years of studying and treating more than 6,000 polio survivors, the most prominent and disabling Post-Polio Sequelae is fatigue. This fatigue is not just physical but what polio survivors describe as “brain fatigue”. In the 1990 International Post-Polio Survey, between 70% and 96% of respondents having fatigue also reported difficulty with *concentration, focusing attention, mind wandering, memory, thinking quickly and word finding;* 77% reporting moderate to severe difficulty with these cognitive tasks[1]. Importantly, these reported impairments were seen in polio survivors in their 40s and never were associated with dementia.

LABORATORY FINDINGS: Our studies have uncovered a relationship between fatigue, impairment of brain activation and cognitive symptoms:

1) Subjects reporting severe fatigue and word finding difficulty had clinically abnormal or significantly lower Animal Naming Test scores as compared to subjects with mild fatigue[2];
2) Slowed performance on the most difficult tests of attention and information processing speed were associated with lower scores on word finding tests[3];
3) A significant inverse relationship between Animal Naming Test scores and plasma prolactin suggests that a reduction in brain dopamine secretion is related to impaired naming ability and support decreased dopamine secretion, possibly secondary to poliovirus damage to the basal ganglia, underlying not only fatigue and impaired attention but also word finding difficulty[4].
4) Polio survivors report a "tip-of-the-tongue" phenomenon characterized by difficulty naming familiar objects and people (sometimes even family members), difficulty that increases as fatigue worsens[5]. This complaint is similar to that in Parkinson's disease patients who also report "tip-of-the-tongue" word finding difficulty as well as "excessive" and sometimes disabling fatigue. Parkinson's patients and polio survivors are similar in that both have damage to dopamine producing neurons.

CLINICAL IMPLICATIONS: The association between subjective and measured impairment of cognitive functions with "brain fatigue" supports the hypothesis that symptoms of post-polio brain fatigue are related to a decrease in dopamine release, causing a reduction in brain activation, and are not symptoms of dementia[1-4]. Therefore, administration of in-office mental status testing (such as the Mini-Mental State Examination) to polio survivors may artificially reduce polio survivors' scores and unnecessarily frighten them with the possibility of having dementia. Any decreased mental status examination test scores on items where concentration and word finding are required (e.g., MMSE items 2, 4, 5, 6,10) should be reported with caveats including the patients' subjective level of fatigue during testing, time of day, their history of subjective concentration and word finding difficulties and whether they experienced the "tip-of-the-tongue" phenomenon during testing.

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Polio survivor says life-changing leg braces should be funded by health system

Source: <www.stuff.co.nz>, February 27,2018

Polio survivor Gordon Jackman can walk freely for the first time in his life thanks to life-changing leg braces. At the age of 62, Gordon Jackman finally knows what it feels like to walk freely. Jackman, who was diagnosed with polio before his first birthday, has become the first New Zealander to be fitted with carbon-fibre orthotic leg braces, developed by a pioneering United States orthotic specialist. But with no Government funding available for

the expensive and life-changing technology, the Wellingtonian fears many other Kiwis might not be so lucky.

"*At age 62, having had polio all that time, I never imagined in my life I would feel these things and experience these things*", he said. "*So it's sort of like getting wings and a motor*."

Although polio has been eradicated in most countries, and all countries in the Western Pacific region, there are about 6000 New Zealanders who still have the incurable disease, which affects the bowel causes meningitis or paralysis. Jackman is one of those people and had lived with paralysis and severe pain in his legs most of his life.

The braces are the only ones of their kind in the world, and help people walk by realigning bones in the foot and leg. The braces, which are made with similar technology to that used to manufacture prosthetic limbs, such as those worn by New Zealand Paralympic gold medallist Liam Malone, work by realigning leg and foot bones to their correct position.

As well as making walking a lot easier, Jackman's crippling pain has all but ceased.

But at a cost of $35,000 the braces are not cheap. Jackman believes they should be funded by the health system, saying the cost would be far less than that incurred by injuries from falls, amputations and expensive surgeries like hip and knee replacements.

"*In the long run, it's probably the best investment I've ever made in myself. But at the moment that's not within the reach of many, many New Zealanders*."

He described the change in his daily life as extraordinary, with his improved posture even improving his singing. "*When I stand, I'm totally balanced and I can be utterly relaxed, which I've never been in my life*."

Jackman set up the Duncan Foundation, an offshoot of the Duncan Charitable Trust, in November. It helped bring the clinician behind the technology, Marmaduke Loke, to New Zealand to meet with other polio survivors.

Jackman said the inadequacy of current orthotics and associated medical care was the biggest complaint among respondents of a recent member survey.

He plans to submit a proposal for funding with joint agencies to the Ministry of Health and Minister for Disabilities Issues, Carmel Sepuloni later this year.

Loke, from Carlsbad near San Diego, met with other prospective clients across the North Island last week, and will return to New Zealand in a few months' time with more custom-designed braces. Loke likened the quality of the current frames, made of thermoplastic, to the technological equivalent of "old Polaroid cameras".

It takes him up to two weeks to design one of the new carbon-fibre braces, compared with just 45 minutes for the thermoplastic versions.

"*We have 26 bones in the foot that have to be realigned in three dimensions, and when you align properly, the human body can stand very efficiently*", he said.

* * *

Polio Connections Quiz

Source: Polio SA Newsletter, Issue 128, Summer 2017

Many famous people had polio, and you probably never knew it!

1. What do Alan Alda and Donald Sutherland have in common (other than overcoming polio)?
Both played Hawkeye Pierce (Alda on TV/Sutherland in the movie M*A*S*H).

2. What is the connection of Elvis to infantile paralysis (another name for polio)?
He had a picture taken of him getting the Salk vaccine to show it was OK.

3. Who wrote, “Save the Last Dance for Me”?
Polio survivor Doc Pomus (Jerome Felder) wrote it for his wife who loved to dance.

4. What famous director had polio?
Francis Ford Coppola.

5. What famous violinist had polio?
Itzhak Perlman.

6. What connection is there to the famous Steiff Teddy Bears?
Margarete Steiff, the German seamstress who made the famous bears, had polio.

7. What polio survivor invented an artificial heart?
Paul Winchell (he was also the voice of Tigger).

8. Who was a Physical Therapist with polio patients before she was an actress?
Olympia Dukakis

9. Name 2 famous people whose wives had Polio.
John Nordstrom’s wife.
Dick Francis’ wife Mary (who is believed to have written or contributed highly to many of his books until her death in 2000).

10. Who had the earliest recorded case of Polio in the UK in 1773.
Sir Walter Scott.

Navigating the National Broadband Network (NBN)

ideas *Information on Disability Education and Awareness Services*

Source: Newsletter of IDEAS, March/April 2018, pp 7-10

The National Broadband Network (NBN) is changing the way you access your internet and fixed telephone services and is being rolled out across Australia. This process is happening right now and is ongoing. The switch over is scheduled to be completed nationwide by 2020 and will affect landline telephone customers, not just internet broadband customers. If you have not migrated to the NBN by the date the copper network is disconnected in your area, then you will not have any home phone or internet connection. This is a safety concern, especially for people who are older or have a disability.

How can you check if you have access to the NBN?

If you have not already switched over to the National Broadband Network (NBN), check your address either online at <www.nbnco.com.au> or by phoning NBN Co on 1800 687 626 to find out:

1. When you will be able to switch over to the NBN.
2. When the legacy copper network in your area will be phased out and permanently disconnected.
3. Which technology you will be using to access the NBN (this is especially important if you are a regional or rural customer).

Technology Types

There are many types of technology associated with the NBN, as it is a Multi Technology Mix (MTM) network. You can call NBN Co or use their website to find out which technology will be rolled out in your area and when. There are seven different connection types:

1. Fibre To The Node (FTTN)

This is the most common connection method. If you are a FTTN customer, you will be connected to the fibre network via a “node” or box which will be installed somewhere in your neighbourhood (within 700 m of your address).

2. Fibre To The Premises (FTTP) or Fibre to the Home (FTTH)

This will only be available in some areas but is viewed as the best connection type. Instead of connecting to a node in your neighbourhood, you will have fibre cable installed all the way to your dwelling. This will provide an ideal connection to the network with maximum download and upload speeds.

3. Fibre To The Basement (FTTB)

If you live in an apartment, this will be your connection type. Fibre will be installed to the apartment block’s telecommunications room (generally in the basement). From there, it will be distributed throughout the building via whichever cable technology is already in place. This could be copper or Ethernet/LAN (Local Area Network) cabling, depending on the age and location of your apartment building.

4. Fibre To The Distribution Point (FTTdp)

Fibre cable is run along each street and connected to the existing copper at the closest possible point to your premises, also known as ‘Fibre to the Curb’ or ‘Fibre to the Driveway’.

5. Satellite (Sky Muster)

This is the satellite component of the NBN which is for rural and remote customers who cannot access the Fixed Wireless or Fibre networks. This is a completely different technology which requires a satellite dish to be installed at the premises to communicate with a satellite.

6. Fixed Wireless

Regional and rural customers are connected to the fibre national broadband network via a fixed ground-based wireless tower. Fixed wireless essentially uses the same technology and wireless spectrum as existing 4G mobile networks. This is an in-between technology which uses both wireless and fibre technologies.

7. Hybrid Fibre-Coaxial (HFC) / Cable

This connection method is utilising the pre-existing cable network in certain urban areas.

This network was previously used to connect customers to cable TV. This connection type is using one of the oldest technologies in the greater NBN network and is experiencing significant congestion issues. It will be periodically phased out in all regions except for 25,000 premises in Redcliffe, QLD in Brisbane's north east.

Connecting to the NBN

NBN Co does not sell services to the public. To use the NBN, you will need to sign up to a contract with a telephone and internet service provider, like Telstra or Optus. You will need to contact your chosen service provider directly to connect the NBN, report a fault or to troubleshoot your connection. There are many providers to choose from and many packages and speed options which can all affect your end user experience of the NBN.

Speed and connection problems

Some customers have experienced connectivity issues or unusably slow internet speeds when initially connecting to the NBN due to insufficient bandwidth being purchased by the service provider for their local area. You can test your internet connection speed by using Ookla's online speed testing service. This can be accessed online by going to <www.speedtest.net> on a web browser on any device connected to your NBN service or by downloading and using the SpeedTest app which is available on the Google Play Store for Android devices, or the Apple iOS AppStore for iPhone or iPad users. If you are not getting the speeds you are paying for, you may be entitled to a refund.

Telecommunications Industry Ombudsman (TIO)

If you are unhappy with your service and are unable to resolve the issue with your service provider, you can make a complaint to the Telecommunications Industry Ombudsman. The Ombudsman provides an independent service which helps small businesses and residential customers who have a complaint about their telephone or internet service provider. It can make a decision on how the complaint is resolved.

The NBN and Medical and Fire alarms

Your personal medical alarm or auto dialler may not work properly once you have migrated to the NBN network. You need to contact your personal alarm supplier or monitored service provider and ask if your service will be affected by the changeover. If it is going to be affected, you need to find out what you can do to make sure your personal alarm still works properly. The changeover can affect monitored and unmonitored personal alarm services as well as auto diallers, which connect to family or friends as opposed to a monitored service.

Monitored or auto-dialling fire alarm systems may also be incompatible with the NBN. It is extremely important that if you have one of these devices and are switching over to the NBN, that you contact your fire alarm supplier or monitored service provider and ask if your alarm will be affected by the switch, and if so, what you need to do to make sure your fire alarm still works correctly.

For more information you can contact IDEAS, NBN Co, the Telecommunications Ombudsman or your chosen telephone and internet service provider.

Contacts

NBN Co Freecall: 1800 687 626
Website: <www.nbnco.com.au>

Telecommunications Industry Ombudsman
Freecall: 1800 062 058
Website: <www.tio.gov.au>

* * *

2018 Polio Program Activities

Saturday 22nd September	**Panthers** **1 Bay Street** **Port Macquarie**	**Polio NSW Country Conference** ***(see details on page 1)***
Thursday 11th *to* Sunday 14th October	**Stamford Grand** **Glenelg** **South Australia**	**Polio Australia's** **8th Polio Health and Wellness Retreat** **<www.polioaustralia.org.au/retreat-2018/>**
Wednesday 21st November	**Burwood RSL** **96 Shaftesbury Road** **Burwood**	**Polio NSW AGM and Seminar** ***Speaker to be confirmed***

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* * *

Have you added your details to the Australian Polio Register?
www.australianpolioregister.org.au

Polio Australia
Representing polio survivors throughout Australia

Volume 8, Issue 2

Polio Oz News

June 2018—Winter Edition

Polio Australia's 10 Year Anniversary!

August 2018 marks Polio Australia's 10th Anniversary, and what an incredible 10 years they've been! Here are a few of the highlights.

Where It All Began

In May 2007, all the State Polio Networks formally met in Parramatta, Sydney, to debate how a National Plan might be developed—with input from all stakeholders—to ensure that polio survivors receive the information, the services, and the support they need into the future.

Incorporation

By August **2008**, a Memorandum of Understanding was developed and agreed by each State Network, a Constitution developed and adopted, and Polio Australia Incorporated became a reality. Gillian Thomas was elected as inaugural President by the Board, made up of 2 representatives from each State Network.

Office Opening

In January **2010**, a small grant and a private donation enabled Polio Australia to employ a part-time National Program Manager (Maryann Liethof) and open our national office in Kew Melbourne.

The first of what has become our annual Polio Health and Wellness Retreats was held in Sydney.

This was also the year Polio Australia attended Parliament House, Canberra to Launch the Parliamentary Friends of Polio Survivors Friendship Group.

Staff Funding

In **2011**, a three-year grant from The Balnaves Foundation allowed Polio Australia to offer Maryann a full time role.

Government Lobbying

2012 was the year that Polio Australia was successful in instigating the House Of Representatives Standing Committee on Health and Ageing *Public Roundtable Forum on Post-Polio Syndrome/Late Effects of Polio (PPS/LEoP).*

Later that year, 60 polio survivors and their supporters visited Parliament House in Canberra and met with their respective MP's to discuss the three recommendations made in the Roundtable Report.

We also published our first resource - *The Late Effects of Polio: Introduction to Clinical Practice* (written pro-bono by the GSK Medical Team).

And at its AGM, Dr John Tierney PhD OAM, was elected as President, a position he held until the end of 2017.

Raising The Profile

In **2013**, Polio Australia gave evidence at an NDIS public hearing in Canberra arguing against the 65 year cut off—this evidence was widely broadcast in the media.

Gillian Thomas appeared on ABC's TV program *Q&A — An Audience with Bill Gates* where she was able to ask a question relating to strategies to *"get governments to shoulder their responsibility and fund essential post-polio services".*

Clinical Resources

In **2014**, Polio Australia facilitated its first *"Understanding the Late Effects of Polio"* workshop for 23 health professionals in Victoria. This session provided important feedback and statistical data to build on for a future Clinical Practice Workshop program.

Thanks to a private donation, we were able to produce *"The Late Effects of Polio: Managing Muscles and Mobility"* resource for health professionals.

(cont'd P5)

Polio Australia
Representing polio survivors
throughout Australia

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Inside this issue:

> ***"Winter is the season of recovery and preparation."***
>
> **~ Paul Theroux ~**

President's Report

Gillian Thomas

I take great pride in reporting in this 10th Anniversary edition of Polio Oz News. In 2005, when I first proposed the idea of a national body to the State Polio Networks, little did I know that we would be thriving in 2018. As the inaugural President of Polio Australia, and long term President of Polio NSW, I worked closely with Neil von Schill, who was very well known in New South Wales. Tragically, Neil passed away in 2014, following a series of strokes, but I know he would have been equally delighted with how Polio Australia has evolved over the years.

During this time, Dr John Tierney PhD OAM, had joined the Boards of both Polio NSW and Polio Australia, taking on the role of PA's President from 2013 to 2017. As an ex-Federal Senator, and experienced Government Lobbyist, John was instrumental in helping us build our profile in Canberra. We have seen many governments come and go since our first visit to Parliament House in 2009! However, we now have 5 bi-partisan Parliamentary Patrons, as well as a Parliamentary Friends of Polio Survivors Friendship Group, all of whom are aware that *"We're Still Here!"*. John has now 'retired' and is in the process of writing his memoirs; I can't wait to read them.

I have also enjoyed seeing Maryann grow in her role as National Program Manager over the years, bringing together projects and events many on the Board thought would be impossible to achieve, such as the 2016 Asia-Pacific Post-Polio Conference in Sydney. Up until last year, Maryann, John, Shylie (our bookkeeper), and myself were the 'Team'; and John and I work on a purely volunteer basis. Now, thanks to consistent lobbying and much hard work, we have funding from the Department of Health to run Clinical Practice Workshops across Australia, and additional funding from Spinal Life Australia; all of which has resulted in an expanded 'Team'. These additional resources mean that, as an organisation, we are in the best position we have ever been to fulfil our original Mission *"to standardise quality polio information and service provision across Australia".*

This leads me to the subject of Paul's article on page 4, where he has invited all states to run information sessions for polio survivors. Polio SA has already benefited from this offer, and Polio NSW has also taken up the invitation, with Paul presenting to NSW members in Sydney in June and Port Macquarie in September.

Finally, as Polio Australia celebrates its 10 year anniversary, we are now seeking younger polio survivors living in Australia – aged 20 to 50 years of age (most likely born overseas) – who would be interested in joining a focus group (via Skype or telephone) to advise on the content of a dynamic/interactive online information package which will appeal to you. We are currently developing specific resources and supports to assist younger survivors to manage their condition into the future. Most of the current information on the LEoP has been developed with older Australian or European polio survivors in mind, which means that younger polio survivors are not connecting with either Polio Australia or the state Polio Networks. So, if you would like to be part of this focus group, please contact us at: office@polioaustralia.org.au or Ph: 03 9016 7678. ⬢

Gillian

From the Editor

Maryann Liethof
Editor

I can't say I am fond of winter's short days and, sometimes, howling winds that blow your umbrella inside out! However, down here in Melbourne, whilst some mornings have hovered around the 3°C mark, we've been enjoying blue skies in the afternoon. Since January 2017, I have really loved looking out of my 6th floor window and watching the days drift past.

This is considerably different to when I first opened up the Polio Australia office on the first floor, with no window at all. It's hard to believe that was 8 years ago! Even more amazing is that Polio Australia has been going for 10 years, in spite of the financial hardship we have had to endure. There are a number of staunch supporters who have helped us through, and President (and Business Manager), Gillian Thomas, has performed absolute magic with what little funds we've had.

I am absolutely delighted to now have a bona-fide 'Team' to work with, all of whom can be viewed on Page 5. Steph and Jake (below) are the two newest recruits, and are already contributing well to Polio Australia's work.

Our Clinical Health Educator, Paul, has been very busy running clinical practice workshops for health professionals, but found himself in front of 120 polio survivors and their supporters in Adelaide in May. An incredible turn out! Read more on Page 4. One of the topics people were keen to learn more about is how to manage pain, and you can read Paul's article on Page 10.

Rachel, our Health Promotions Officer, has been working on both our 2018 Health and Wellness Retreat Program (Page 6) and updating Polio Australia's websites. She has set up a page for readers to tell us their experience of Polio Australia (see Page 5), and expanded our 'Support Us' webpage (see Page 7). It's not too late to support our work through an 'End of Financial Year' donation!

Another article of interest was written by John MacFarlane, previous President of the European Polio Union, and now author of the PoPSyCLE blog site. John explores the demise of polio support groups on Page 9.

There are also two, very different, new polio books to review on Page 12. And Polio NZ is promoting their Health and Wellness Retreat on Page 18.

Should be a bit of something for everyone! ⬢

Maryann

New Team Members

Steph Cantrill – Polio Community Officer (VIC)

I have worked as an Occupational Therapist for many years, beginning my career in western Victoria and then returning to Melbourne to work in rehabilitation hospitals. I spent four years working in community development in India, then came back to Melbourne once again. I currently work in outpatient rehabilitation in the area of chronic pain.

I began my role as Polio Community Officer (Vic) with Polio Australia on the 8th of May for 3 days a week. It's been great meeting with polio survivors and the people who work with them, and learning about all the complexities of the Late Effects of Polio. I'm really looking forward to getting out into communities to share what I've learned and help people get connected with the services and support they need. ⬢

Jake Malsbury – Administrative Officer

I joined the team at Polio Australia in May of 2018 for one day a week. I am currently in the first year of my Masters of International Development Practice at Monash University.

I am passionate about health and human rights, and believe that every individual has the right to access health care to maintain a healthy wellbeing. I am interested in learning more about the experiences of polio survivors, as well as reaching out in cross-cultural settings to work with younger cohorts affected by polio.

I am both very honoured and excited to contribute to the mission of Polio Australia, and hope that our work will reach out to more and more audiences with every coming year. ⬢

Polio Survivor Information Session In Adelaide

By Paul Cavendish
Clinical Health Educator, Polio Australia

On Saturday 12 May 2018, Polio Australia and Polio SA hosted an Information Session for polio survivors, to better equip them with knowledge about the Late Effects of Polio (LEoP). The session was held at the Tea Tree Gully Community Centre, approx. 20kms north-east of the Adelaide city centre.

On the lead up to the event, we were fortunate to have an article published in the Adelaide Advertiser, raising awareness of the LEoP and promoting the information session. From this article, we had an overwhelming response, with over 80 polio survivors contacting me who were new to Polio SA and Polio Australia

The session focused on navigating the medical and health system, discussing what to look for within the various services, getting the most out of working with health professionals, and who is best to help with various symptoms. We also looked at some effective self-management strategies and had time for questions from attendees.

It was great to see the response and hear the story of how someone met an old friend from many years ago.

We were fortunate to have Dr Nigel Quadros attend to discuss the role of the Rehabilitation Specialist, and also hear about his research into the LEoP. Hopefully, South Australians will be able to contribute towards finding answers as to how the LEoP can be reduced!

This is only the beginning of what Polio Australia wants to achieve in providing support and information to polio survivors. I am excited about returning to Adelaide in October for the Retreat, and to deliver another session. I also encourage other Polio Networks to enquire about options for running a similar session.

Some comments on the session follow:

I have purposely remained ignorant of PPS as I did not want to "talk myself" into any of the symptoms. I now see the wisdom of being aware so I can look after my health properly — thank you so much.

Very practical (but also rather confronting). I generally am in denial in every day life.

Thank you so much for this great presentation. It was greatly appreciated. To hear that my symptoms are "normal" and I'm not alone was wonderful.

The 120 polio survivors and their supporters who attended this session was unprecedented. However, it proves that there are so many more polio survivors in the community still looking for information on the Late Effects of Polio. This is why *"We're Still Here!"* ⬢

Read Paul's ESSA Article here: ***Working with Polio Survivors—An Interview with Paul Cavendish***

Polio Australia's 10 Year Anniversary! *(cont'd from P1)*

Rotary Partnership

In **2015**, Polio Australia partnered with Rotary District 9685 (Sydney Harbour to the Central Coast of NSW) to deliver a pilot program of 8 Clinical Practice Workshops, providing training for 140 health professionals. The 'Polio Health' website was launched, providing a valuable resource for health professionals and polio survivors alike.

International Conference

In **2016**, Polio Australia held the first ever *Australasia-Pacific Post-Polio Conference: Polio — Life Stage Matters*, comprising 23 Keynote Presenters, 38 additional Oral Presenters, and 8 Poster Presenters, as well as attracting a total of 229 delegates from 14 countries.

Building The Team

2017 is the year things really started changing thanks to funding from the Department of Health of $150,000 pa x 3 years to establish the LEoP Clinical Practice Workshops Program; and $100,000 pa x 2 years grant from Spinal Life Australia for the purpose of *"achieving financial security for Polio Australia into the future"*. Maryann went from being the only sole employee to a manager of: Samantha O'Meara (Bequests Officer—since resigned); Rachel Ingram (Health Promotions/Admin Officer); Paul Cavendish (Clinical Health Educator); and Bonnie Douglas (Fundraising Officer). Shylie Little continues to provide bookkeeping and admin support 2 days a week from the Polio NSW office.

Educating Health Professionals

2018 marks the year the Clinical Practice Workshops Program has started making inroads, with 29 workshops held in all states of Australia in the first half of the year. This equates to 369 additional health professionals trained in the Late Effects of Polio. Another private donation has recently enabled us to employ Steph Cantrill in the role of Polio Community Officer for Victoria. Her job is to work with the Victorian state Polio Networks to reach out to polio survivors in the community who are unaware of the LEoP and what services they can access, including younger migrants. We have also employed Jake Malsbury to provide additional Workshop admin support one day a week.

Seeing Us Through

Polio Australia has often struggled to produce and deliver information and activities (such as the annual Health and Wellness Retreats) over the years, with severely limited financial and human resources. However, we have also been blessed with enormous support from a few incredibly generous donors and dedicated supporters. Ten years on, we are finally realising a number of goals discussed during that 2007 National Plan forum, and look forward to what the future has to bring! ⬢

- Ed

We would love to hear from our readers with any comments or stories about how Polio Australia may have influenced the way you are now managing the Late Effects of Polio, or information you have found particularly relevant, or anything else you would like to share with us!

Click here to tell us *"How has Polio Australia helped you?"*

With permission, your contribution may be posted on our website, social media, or used in a future edition of *Polio Oz News*.

During August, make sure you are following us on Facebook.

L-R: Rachel, Paul, Maryann, Bonnie, Jake, Steph

2017 Retreat Participants

Polio Health and Wellness Retreat

Body / Mind / Spirit

Stamford Grand in Glenelg, South Australia
Thursday 11, Friday 12, Saturday 13 and Sunday 14 October 2018

Registrations Now Open!

Polio Australia will once again be facilitating its 4 day / 3 night Polio Health and Wellness Retreat for polio survivors and their partners/family members from Thursday 11 to Sunday 14 October, 2018 in the beautiful seaside suburb of Glenelg, South Australia. **Limited to 70 participants: book early to avoid disappointment!**

The holistic 'Body / Mind / Spirit' theme will continue and include sessions such as:

- Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- Hydrotherapy and exercise options
- Latest orthotics, aids and equipment displays
- Chair Dancing and Meditation Sessions
- Activities To Keep The Mind Active
- Creative Workshops

www.polioaustralia.org.au/retreat-2018

Cost:
$450 per person for twin share/double occupancy
$500 per person for single room occupancy

Note:
Ocean View rooms will be allocated to 'early birds'

Includes:

- All sessions and workshops
  — *except hydrotherapy + $20*
- Friday Movie Night: *"Breathe"*
- Saturday Night Entertainment: *Celtic Music Club*
- 3 nights accommodation—Thursday/Friday/Saturday
- 3 breakfasts—Friday/Saturday/Sunday
- 3 lunches—Friday/Saturday/Sunday
- 3 dinners—Thursday/Friday/Saturday

Register Now

Grand City View Accessible Room - Bathroom

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 January to 30 April 2018. Without you, we could not pay our rent, core operating expenses, or management staff!

Hall of Fame

Jill Pickering: $9,000 rent / $10,000 Retreat / $20,000 Community Development Worker (Vic)

Total—$39,000

General Donations

Jill Burn   Irene Houston   Karen Myers   Liz Telford

Gillian Thomas   Johanna Twigg   Mel White

Total—$1,440

Walk With Me Donations

Erica Nuttall   Phil Slattery   Pam Stace   John Watson

Total—$376

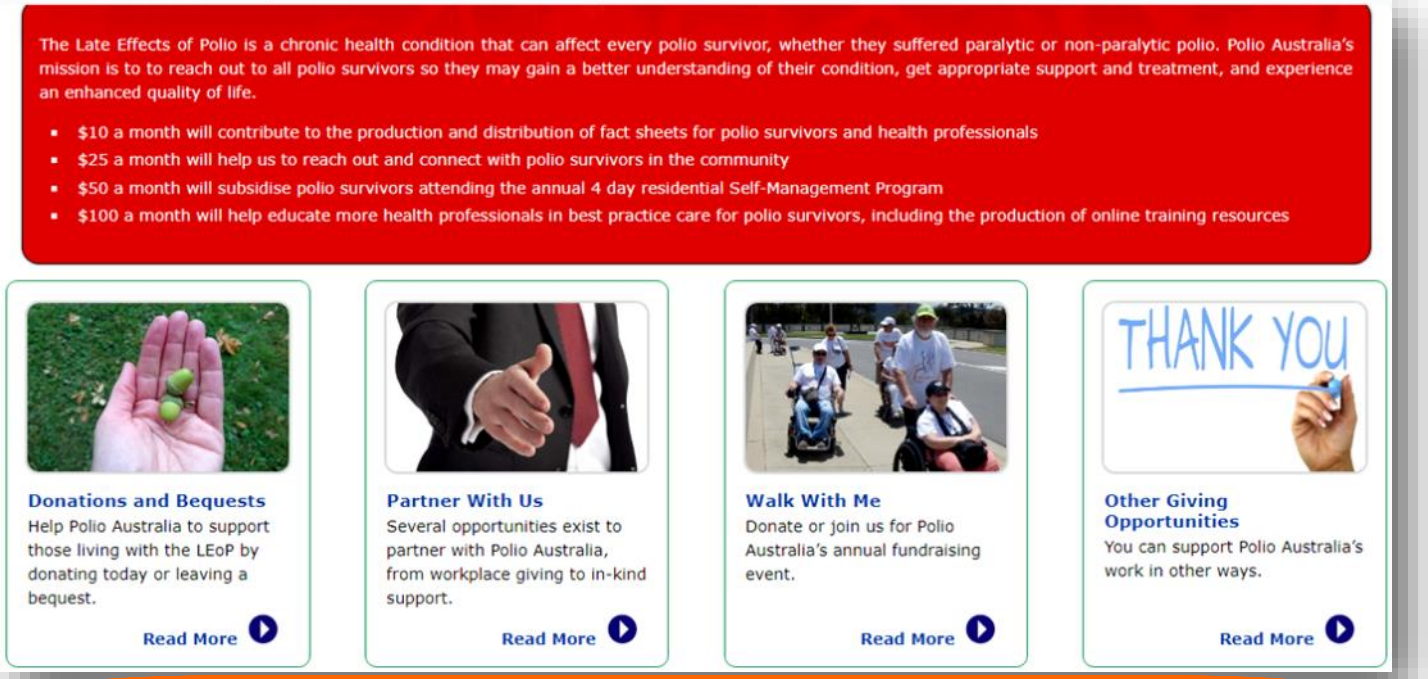
Rotary Club Donations

Rotary Club of Thuringowa Central (Qld)

Total—$1,500

Grand Total—42,316

Check our new 'Support Us' webpage here: www.polioaustralia.org.au/support-us



The Late Effects of Polio is a chronic health condition that can affect every polio survivor, whether they suffered paralytic or non-paralytic polio. Polio Australia's mission is to to reach out to all polio survivors so they may gain a better understanding of their condition, get appropriate support and treatment, and experience an enhanced quality of life.

- $10 a month will contribute to the production and distribution of fact sheets for polio survivors and health professionals
- $25 a month will help us to reach out and connect with polio survivors in the community
- $50 a month will subsidise polio survivors attending the annual 4 day residential Self-Management Program
- $100 a month will help educate more health professionals in best practice care for polio survivors, including the production of online training resources

Donations and Bequests
Help Polio Australia to support those living with the LEoP by donating today or leaving a bequest.

Read More

Partner With Us
Several opportunities exist to partner with Polio Australia, from workplace giving to in-kind support.

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Walk With Me
Donate or join us for Polio Australia's annual fundraising event.

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Other Giving Opportunities
You can support Polio Australia's work in other ways.

Read More

Polio Australia is now fundraising with **Entertainment Book**! You can support us by purchasing an Entertainment Book and also enjoy valuable up to 50% off and 2-for-1 offers for many of the best restaurants, cafes, attractions, hotels, travel, shopping and more! Books are available **throughout Australia, New Zealand and Bali**: www.entertainmentbook.com.au/orderbooks/9s50832

Regulation of Mobility Scooters

COTA Australia Submission to the Senate Inquiry into the Need for Regulation of Mobility Scooters

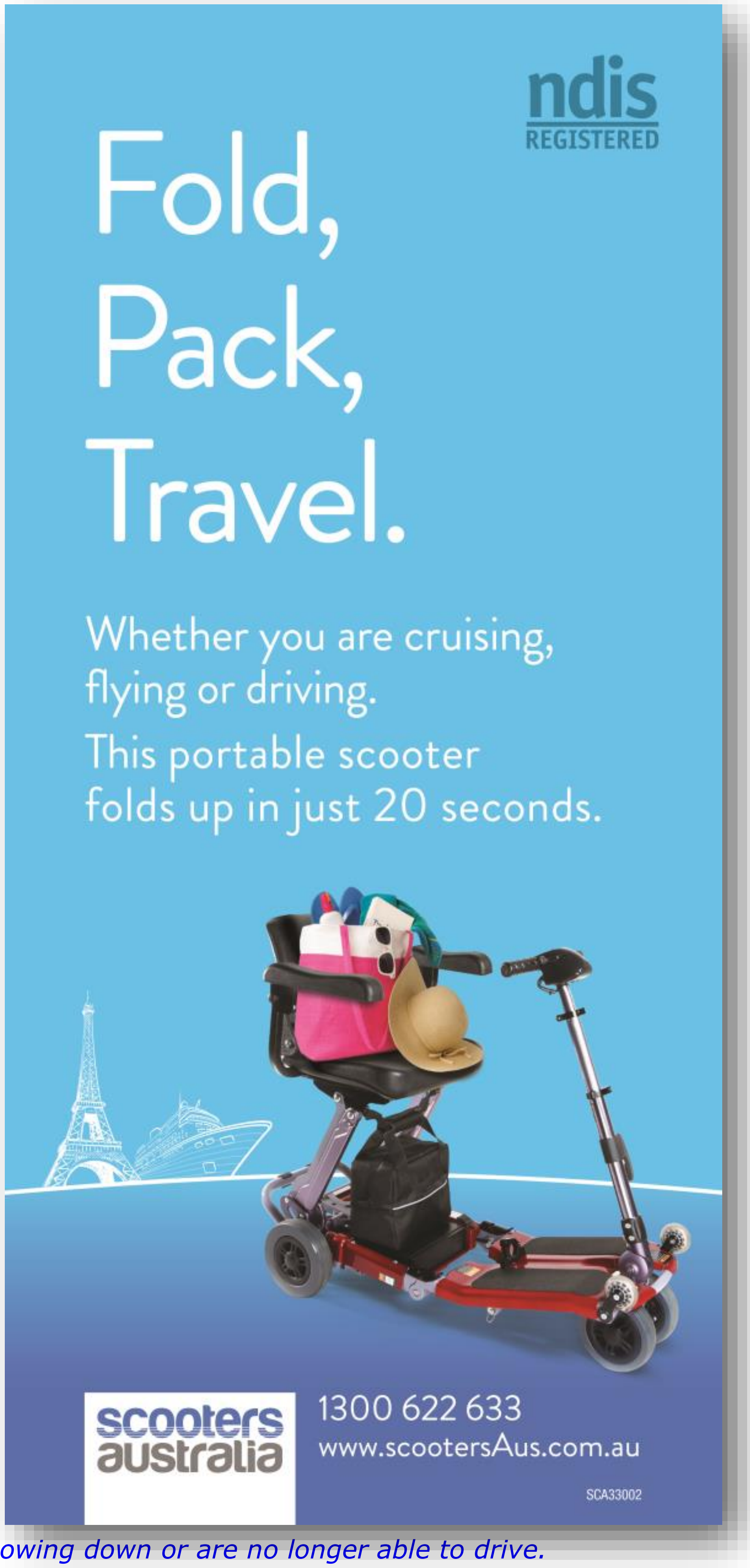
Source: www.cota.org.au – 13 March 2018

COTA Australia is pleased to have the opportunity to contribute briefly to this Senate Inquiry, on an issue of importance to many older Australians – mobility scooters. Indeed, Scooters Australia claimed in 2009 that the overwhelming proportion of mobility scooter users are in the 70+ age group and in fact, in the previous few years, most purchasers were aged over 80.

While we recognise that mobility scooters and motorised wheelchairs are equally important to many younger people with disability, as COTA's constituency is older Australians and our focus is on ageing, we will confine our comments to the experience and needs of older people with limited mobility or a disability.

We note that the Senate Committee clarified its terminology during the course of the Inquiry, to treat motorised mobility scooters and motorised wheelchairs as separate vehicles, to be considered separately in its deliberations. COTA's submission preparation focused primarily on motorised mobility scooters. Although wheelchairs have a different function to scooters, and their users may not have the ability to transfer from it without assistance, we believe that much of what we say regarding scooters is relevant to motorised wheelchairs.

COTA's primary view is that mobility scooters bring independence and movement to many people who would otherwise have difficulty getting around in their communities to undertake simple tasks taken for granted by most people. The capacity to visit friends and family, shop, attend appointments and be part of community activities are crucial to quality of life and to enable older people to remain independent and in their own homes for as long as possible. Mobility scooters are also particularly important to older people in areas with limited public transport.



Older people want to be part of their communities. They want to get out and about, they want to stay fit and active and they want to keep up with friends and family, and with interests and volunteering, even if they start slowing down or are no longer able to drive.

We should therefore do all we can to make our community easy for pedestrians of all ages to use safely – and pedestrians now include those using mobility scooters, walking aids, pushers and prams, wheelchairs etc.

– Jane Mussared, Chief Executive, COTA SA

Read full story and link to Submission here. ⬢

Is This The End Or A New Beginning?

The following article appeared on the PoPSyCLE blog site, hosted by John MacFarlane, previous President of the European Polio Union. It has been reprinted with permission.

Last Sunday [22 April 2018] saw a sad event as the Post Polio Awareness and Support Society of British Columbia — PPASS BC, Canada, held its last ever meeting. The fact that this group has had to cease operation may not be earth shattering in itself but it is symptomatic of the problems being faced by many of the polio Survivor Support Groups all over Europe and North America as well as further afield. The average age in these geographical areas of survivors is 65 years + and just like the rest of the general population as they get older their energy levels and their ability to travel, organise, petition and generally fulfill the functions needed by the members decrease.

The real question that they and many other disability groups who deal with the more senior people in the population face is who is going to support them in the future. If polio survivors cannot run their own groups due to ever-increasing disability and infirmity, who will? Is this a matter of concern just to them or should it be something that society in general should both become aware of and action?

I know from personal experience in running disability support groups, in various countries, that trying to get people to stand up and take responsibility is never an easy task. All too often you can call a meeting and people will put their hands up and say "*yes, we will help*" but then when called upon the uptake is minimal or non-existent. Should it be the families of those directly affected who take over the task? This brings us to another problem, which is to do with the breakdown of the nuclear family in modern society. At one time, it was not uncommon to have grandparents, parents and children all living under the same roof and supporting each other. Today, there is an ever-increasing demand for housing in all European Societies, part of this result from each part of a family wanting their own home. If you take this model onto a bigger plain, you could see why the support groups are breaking down. Previously if Granny lived with you and had a disability and went to a support group meeting it was common for the son, daughter or who ever lived with them, maybe even grandchildren, to go along and get involved in the running of the organisation that looked after Granny and helped her to have a life with a brighter future.

Should society in general pick up the cudgel? If the answer to this one is yes, who is going to be responsible — government in general, health authorities — WHO? We all know that all arms of caring society and health are in crisis across the world. Can they be expected to take on this extra load when they are not even able to deal with the chronic shortages they have at the present time, many of which are a direct result of the aging population which is looking for even more health through disability and infirmity. The solution seems intractable; family, statutory authority or centralised government are all straining to cope with their current load. Do we have to abandon these support groups and watch them shut down, one by one, and inevitably transfer their case and work load by default to others.

Joan Toone, President of Post Polio Awareness and Support Society of British Columbia – PPASS BC, and husband Terry Toone

Although not an easy thing to say, some may have to go the way of the group in British Columbia. The solution for many of these smaller associations lies in collaboration and cooperation with large organisations. This is especially true of those support groups in Europe and North America who look after polio Survivors. As is well-known, polio as a disease has been drastically reduced and the demographics mean that in time there will be no polio survivors — time and morbidity will inevitability deal with that one. But unless there are drastic medical advances in the next 15-20 years we will still have other Neuromuscular conditions such as Multiple Sclerosis, Muscular Dystrophy, and the like still around. So surely the answer should be that the smaller organisations should in the future look to working with and becoming part of larger support groups. It may not be an ideal solution that some would agree to but it will still mean they have a fora and platform on which to be heard.

(cont'd P10)

Is This The End Or A New Beginning? *(cont'd from P9)*

The demise of any support group large or small is to be lamented and this is especially true of President Joan Toone's Group based in British Columbia. They have made their mark on the polio survivors scene for many years and brought about innovations and social change. It is now our job to learn from the lessons they have given us to carry the torch forward and in so doing ensure that groups that do have a future can thrive and survive.

PoPSyCLE's message to the polio survivors of British Columbia at their closing meeting:

"I write this with a heavy heart as I know this Sunday will be your last gathering in BC. It may well be the last official meeting but the name of your organisation will live on in the annuls of PoPSyCLE as when its formation was proposed for the care, management and treatment of polio survivors around the globe, I asked President Joan would you be Founder Members — the answer was an emphatic YES. Things may not have happened as quickly as we would have liked but the encouragement we received from BC has always encouraged us to fight on.

I first met many of you in Copenhagen 7 years ago and much water has gone under the bridge since then. Firm friendships have been forged across the Atlantic and N. American Continent. These will remain forever. I know my wife and I have a standing invitation to Vancouver Island and we will get there and perhaps meet up with some of you again. Be assured the polio survivors of BC and their indomitable spirit will not be forgotten. We will ensure your legacy lives on and if there is anything we can do for any of you on an individual basis, even if only remotely possible we will do all we can to assist.

A sad day, but a proud one, raise a glass and celebrate all you have achieved — you all deserve a big THANK YOU from polio survivors everywhere for being a role model for the rest of us." ⬢

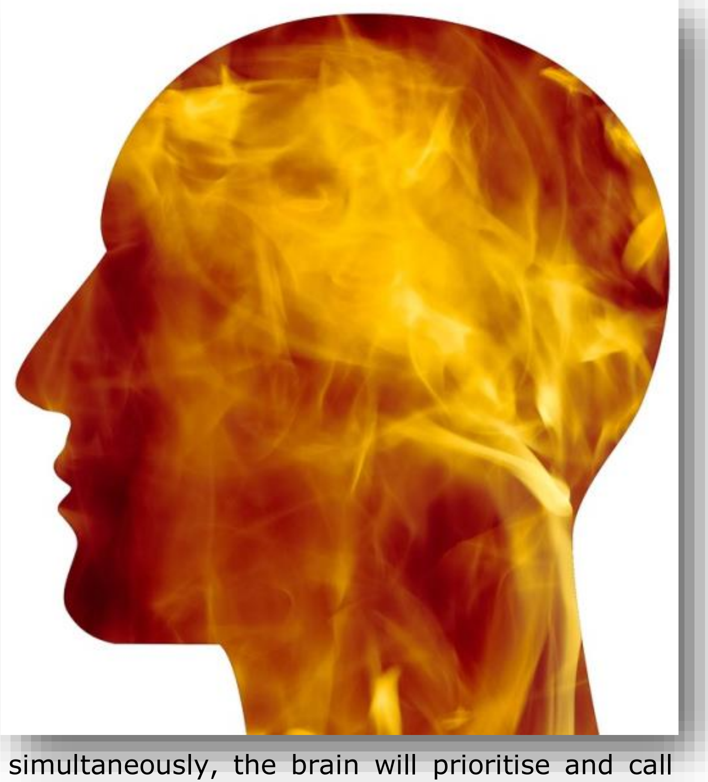
Our Perception Of Pain

By Paul Cavendish
Clinical Health Educator

There are few challenges with the human body so widespread and yet so difficult to explain and treat as pain. There can be many sources of pain which are important to distinguish but the main focus of this article is on how we interpret pain.

In a landmark study published in the highly respected New England Journal of Medicine, researchers used MRI to scan the spines of two groups of people — those who reported back pain and those who didn't. What made this study remarkable, and has subsequently influenced our thoughts on pain perception, is that 52% of the group who reported no pain, had disc bulges – an issue that would be reflective of pain symptoms. Similarly, in this study and others, among those who reported pain, there is not always evidence or a difference in scans, to those who don't report pain. It would be all too easy to dismiss the results of those who reported pain without evidence of 'damage' that there was nothing wrong with them and they were exaggerating their symptoms. It becomes harder to explain why there was evidence of a 'damaged' spine with no pain reported.

There is clearly something happening in how our brain perceives the signals of our sensory nerves. These receptors pick up changes in surrounding tissue from changes in pressure, length, vibration, speed of movements, and chemical compositions from stress / muscle contractions. If there are many of these messages occurring simultaneously, the brain will prioritise and call for more information or back-up to deal with this problem. But could this process be changed? If I am walking with my son and he loses grip of his balloon, he could dart across the road without any warning. Imagine we parked the car and are heading to the beach. I am bare foot. I run to grab my son, not seeing the smashed glass that I land in. In this moment of admonishment of



(cont'd P11)

Our Perception Of Pain

(cont'd from P10)

said child, I don't realise my feet are bleeding. Now consider the opposite situation when I iron. My fingers get close to the iron and I quickly move them away and call "ow!", yet I didn't actually burn myself. My environment (or situation), my previous experiences, and my knowledge, all influence how pain is interpreted.

Quite often when the information above is discussed, many of us interpret that pain is therefore "all in our mind". This is not correct. Our body is sending messages, so it can't just be the mind. There is more potential to influence pain signals and perception of these signals through our brain's ability to modulate, or prioritise, the message when there is persistent pain. It is, however, challenging to achieve changes in how these messages are sent and perceived the longer that pain has been consistently there. To achieve any level of success, we have to realise that we can't beat ourselves - it's not a competition you can win when there is only one player! Pain is telling us important information and if there is a need to 're-set' the level of importance these messages have, we will never change this by ignoring this information, or arguing on their importance with ourself!

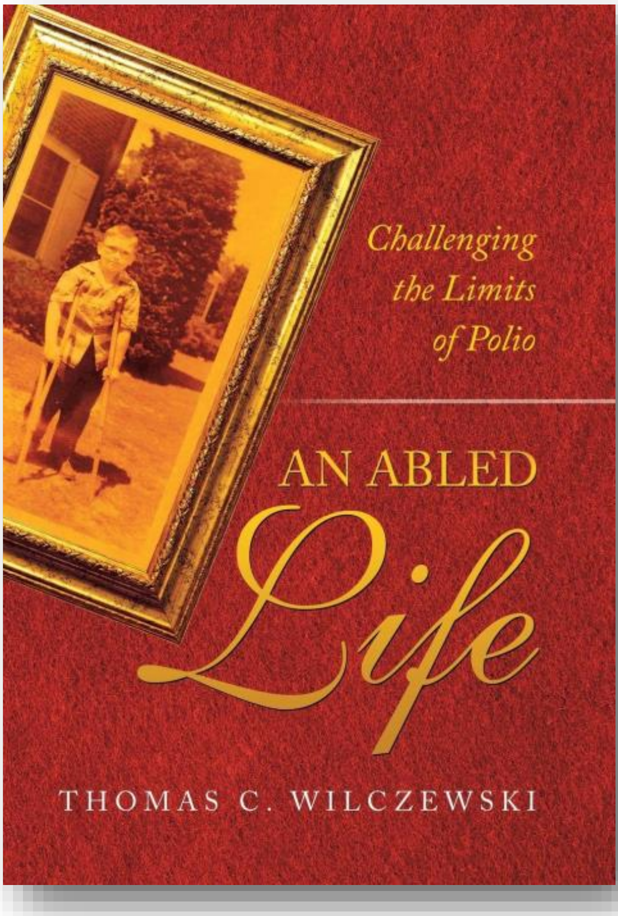
The first step is to understand why we are aware of our pain at different times, more so than others. To do this, record your activities and pain levels for a week. Once you have done this, look for a pattern. Is it happening at the end of the day, or on a particular day of the week? Look at the time you spent with an activity. While there might be pain all the time, there will be times that it gets worse. Take a look at what led up to this situation and identify things you think you could do differently. There are always a few challenges with this process and it is impossible to conquer everything at once. Start with one thing, then another, and so on. Otherwise it's hard to know what may be working or not.

We often use pain as a guide when we do this process. I often have people tell me, *"I know when I have done too much in the garden because I can't move by the end of it."* What we want to establish is time; what time can you tolerate with an activity? The pain should not be worse with this time frame. It may end up to be a small time, and it may be really annoying! This is an important step in 're-setting' your pain signals by avoiding consistent signals of heightened, or strong messages that will occur if you allow pain to be used as a guide. It does not mean this duration you initially set is fixed but we must establish a starting point before trying to finish anything and then build from there.

The concept of pacing is one of the most effective strategies to increase our capacity. Once you have your times for activities, or overall amount for a day, you can start increasing what you do. Again, we want to start with one thing and slowly increase the time and not let pain guide us. Often, the gardener who is learning this re-set will decide to continue with their task after the set pacing time because they feel good and end up paying for it later that day, or the next (or both!). You have to be rigid with your time and not get excited with how you feel.

It is important to consider the sources of pain. This article began by identifying the focus is on pain perception. With a body that has the Late Effects of Polio, pain can come from a range of factors. The above principles can assist but the right orthotic to stabilise joints to improve the energy cost or angles of joints will improve walking capacity and any associated pain that may result. The appropriate brace for assisting our posture and tolerance with sitting and standing is going to improve the capacity in these positions. For further information on decreasing the effects of chronic pain, please view The Pain Management Network or The Pain toolkit. ⬢

An Abled Life: Challenging The Limits Of Polio



Tom Wilczewski was stricken with polio in August of 1949, two months before his fifth birthday. He was confined to an iron lung for over one year. In 1963 he graduated from A. Harry Moore High School, in Jersey City, New Jersey. After graduation he sought employment. It was a time when accessibility for the disabled was not part of society's concerns. He was given many excuses why he could not be hired. The underlying factor was he sat in a wheelchair. After much disappointment in seeking employment, he started an engraving business with his brother Ed which they successfully operated for over thirty five years.

November 27, 1984, was cold and dreary. On that day the life that Tom knew came to a screeching halt. An unscrupulous and incompetent construction crew that had been building a condominium next to his house had undermined the foundation of the home and his business. The family home and Tom's business were destroyed. Tom in his wheelchair with his brother Ed and their nearly blind father barely escaped being trapped in the crumbling red brick dwelling.

The Wilczewski family fought their way back from this devastating blow — Tom with his brother Ed started their business over again at another location in their downtown neighborhood. The high point in Tom's life was marrying Antoinette who was equally accomplished and like Tom had polio.

Book available through Amazon website here. ⬢

A Pound Of Kindness

Click the YouTube image (right) to link to a very special story that happened to Dave Clark, a polio survivor, and this story is being published in a children's book called *"A Pound of Kindness".*

This book will be available in September 2018.

For more details on how to purchase this book, click on the following website:
www.kickstarter.com/projects/1146763627/a-pound-of-kindness-childrens-book

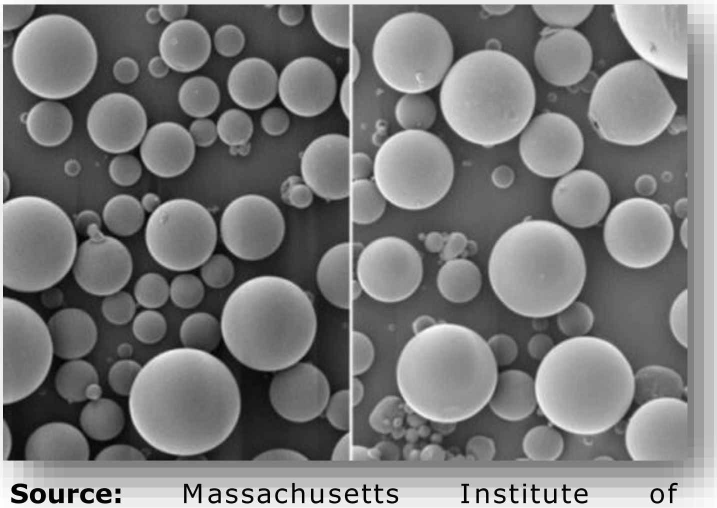
Facebook version

YouTube version

A Single-Injection Vaccine For The Polio Virus

Summary:

A nanoparticle vaccine could help eradicate polio worldwide. The vaccine, which delivers multiple doses in just one injection, could make it easier to immunize children in remote regions of Pakistan and other countries where the disease is still found.



MIT researchers developed these polymer microspheres containing polio vaccine that can be released in two separate bursts.

Credit: Courtesy of the researchers

Source: Massachusetts Institute of Technology – 21 May 2018

A new nanoparticle vaccine developed by MIT researchers could assist efforts to eradicate polio worldwide. The vaccine, which delivers multiple doses in just one injection, could make it easier to immunize children in remote regions of Pakistan and other countries where the disease is still found.

While the number of reported cases of polio dropped by 99 percent worldwide between 1988 and 2013, according to the Centers for Disease Control the disease has not been completely eradicated, in part because of the difficulty in reaching children in remote areas to give them the two to four polio vaccine injections required to build up immunity.

"Having a one-shot vaccine that can elicit full protection could be very valuable in being able to achieve eradication", says Ana Jaklenec, a research scientist at MIT's Koch Institute for Integrative Cancer Research and one of the senior authors of the paper.

Robert Langer, the David H. Koch Institute Professor at MIT, is also a senior author of the study, which appears in the *Proceedings of the National Academy of Sciences* in the week of May 21. Stephany Tzeng, a former MIT postdoc who is now a research associate at Johns Hopkins University School of Medicine, is the paper's lead author.

"We are very excited about the approaches and results in this paper, which I hope will someday lead to better vaccines for patients around the world", Langer says.

Global eradication

There are no drugs against poliovirus, and in about 1 percent of cases, it enters the nervous system, where it can cause paralysis. The first polio vaccine, also called the Salk vaccine, was developed in the 1950s. This vaccine consists of an inactivated version of the virus, which is usually given as a series of two to four injections, beginning at 2 months of age. In 1961, an oral vaccine was developed, which offers some protection with only one dose but is more effective with two to three doses.

The oral vaccine, which consists of a virus that has reduced virulence but is still viable, has been phased out in most countries because in very rare cases, it can mutate to a virulent form and cause infection. It is still used in some developing countries, however, because it is easier to administer the drops than to reach children for multiple injections of the Salk vaccine.

For polio eradication efforts to succeed, the oral vaccine must be completely phased out, to eliminate the chance of the virus reactivating in an immunized person. Several years ago, Langer's lab received funding from the Bill and Melinda Gates Foundation to try to develop an injectable vaccine that could be given just once but carry multiple doses.

"The goal is to ensure that everyone globally is immunized", Jaklenec says. *"Children in some of these hard-to-reach developing world locations tend to not get the full series of shots necessary for protection."*

To create a single-injection vaccine, the MIT team encapsulated the inactivated polio vaccine in a biodegradable polymer known as PLGA. This polymer can be designed to degrade after a certain period of time, allowing the researchers to control when the vaccine is released.

"There's always a little bit of vaccine that's left on the surface or very close to the surface of the particle, and as soon as we put it in the body, whatever is at the surface can just diffuse away. That's the initial burst", Tzeng says.

(cont'd P14)

A Single-Injection Vaccine *(cont'd from P13)*

"Then the particles sit at the injection site and over time, as the polymer degrades, they release the vaccine in bursts at defined time points, based on the degradation rate of the polymer."

The researchers had to overcome one major obstacle that has stymied previous efforts to use PLGA for polio vaccine delivery: The polymer breaks down into byproducts called glycolic acid and lactic acid, and these acids can harm the virus so that it no longer provokes the right kind of antibody response.

To prevent this from happening, the MIT team added positively charged polymers to their particles. These polymers act as 'proton sponges', sopping up extra protons and making the environment less acidic, allowing the virus to remain stable in the body.

Successful immunization

In the *PNAS* study, the researchers designed particles that would deliver an initial burst at the time of injection, followed by a second release about 25 days later. They injected the particles into rats, then sent blood samples from the immunized rats to the Centers for Disease Control for testing. Those studies revealed that the blood samples from rats immunized with the single-injection particle vaccine had an antibody response against poliovirus just as strong as, or stronger than, antibodies from rats that received two injections of Salk polio vaccine.

To deliver more than two doses, the researchers say they could design particles that release vaccine at injection and one month later, and mix them with particles that release at injection and two months later, resulting in three overall doses, each a month apart. The polymers that the researchers used in the vaccines are already FDA-approved for use in humans, so they hope to soon be able to test the vaccines in clinical trials.

The researchers are also working on applying this approach to create stable, single-injection vaccines for other viruses such as Ebola and HIV.

The research was funded by the Bill and Melinda Gates Foundation.

Massachusetts Institute of Technology. *"A single-injection vaccine for the polio virus: Nanoparticles could offer a new way to help eradicate the disease worldwide."*

ScienceDaily, 21 May 2018:
www.sciencedaily.com/releases/2018/05/180521154250.htm ⬢

Why It's So Hard To Wipe Out Polio In Pakistan

By Diaa Hadid

Source: www.npr.org — 26 May 2018

Two young women burst through the door of a health center in a Pakistani slum. One woman sobs. The other tries to explain what just happened.

Nida, 21, and Sahar, 19, are front-line vaccinators — a small but essential role in Pakistan's enormous effort to eradicate the virus. They were going down alleys knocking door-to-door, administering polio vaccine drops to children, when a man pulled out a gun, slammed Nida over the head, snatched her bag and ran away. (Nida and Sahar asked that their last names not be used to protect their safety.)

This slum, in the working-class city of Rawalpindi, is *"a high-risk area"*, says Nosherwan Khan, a member of Pakistan's National PolioPlus Committee, which is affiliated with Rotary International.

"It might be criminal activity. It might be a vaccination attack", says Khan. The violence aimed at vaccinators, whatever the cause, is partly why Pakistan is one of the world's last holdouts against polio, alongside Afghanistan and Nigeria.

Targeting 38 million children

There are some 260,000 polio vaccination workers who fan out across the country, accompanied by 100,000 to 200,000 security personnel to protect them.

This all began after the country reported 306 cases of polio in 2014. That's when the newly-elected government declared polio a national health emergency, says Ayesha Raza Farooq, the prime minister's point person for polio eradication. The government and the U.N. unfurled an ambitious campaign to eradicate the virus, supported by Rotary International and the Bill & Melinda Gates Foundation (which is a supporter of this blog).

There's excellent progress: Last year there were just 8 polio cases. This year, there was one. But getting to zero cases is elusive. And it's a key milestone toward Pakistan proclaiming itself free of the virus. The current ruling government made eradicating polio one of the country's top three priorities.

Even more important than getting down to zero, Pakistan needs to stop the wild polio virus from circulating. *"Even if you have zero cases — the risk is there"*, says Dr. Jamal Raza, president of the Pakistan Pediatric Association and an advocate for vaccination.

(cont'd P15)

Why It's So Hard To Wipe Out Polio *(cont'd from P14)*

Raza said that only 1 percent of polio cases lead to paralysis. But other children who display no symptoms can spread the virus — potentially infecting kids whose immune systems are vulnerable.

Pakistan has an extensive surveillance system, and the country's most recent Polio Eradication Update listed 12 sites where the virus is still circulating. It is still present in parts of the port city of Karachi, slums around Rawalpindi and through a corridor of towns that lead from the Pakistani border to Afghanistan.

What They're Up Against

There are dramatic obstacles to eliminating polio. Violence aimed at vaccinators make headlines — like the mother-and-daughter vaccination team who were gunned down in Quetta, a garrison town near the Afghan border, on January 18. The attacks are inspired in part by preachers who claim vaccines are a Western conspiracy to make Muslims infertile. Others claim vaccinators are spies, a lingering legacy of the CIA using a fake vaccination campaign to find Osama bin Laden in Pakistan nearly a decade ago.

The anti-vaccine activists not only fuel violence but also prompt parents to refuse vaccines. And then there's vaccination fatigue, as health workers repeatedly immunize children.

The Centers for Disease Control recommends four doses of oral vaccine. But Dr. Raza says that's not the case in Pakistan. He said Pakistani children are particularly vulnerable because many of them are undernourished *"and have a poor local immunity."*

"In those children, three or four doses doesn't do it", he says, referring to cases where children had received the four doses and still contracted the virus.

Walter Orenstein, associate director of the Emory Vaccine Center, agrees. In an email to NPR, he wrote: *"More doses are needed in developing countries to reach herd immunity thresholds than in industrialized countries. How many doses are needed is unclear. Ten to 14 doses seems like a lot. But given the need for wiping out the last chains of transmission, better to err on the side of more doses than you need than fewer."*

He adds: *"There is no harm at all from extra doses if you are already immune."* But the regular campaigns have a downside.

Refusal Rates And Viral Protests

In high-risk areas for polio like the Fauji slum in Rawalpindi, vaccinators visit once a month. The virus is circulating in the sewage in the area — suggesting that some residents have the virus but haven't shown symptoms.

"I am not surprised that people are fatigued," says Farooq. *"Our teams are knocking doors in our high-risk areas at least once every month."*

Farooq said scientists told her the refusals *"are not worrisome, it is only when there is a cluster of refusals, blocks of refusals,"* she said. *"We don't see that right now."*

Refusal rates are in fact quite low — *"from 0.1 percent to 0.15 percent"*, says Rana Safdar, coordinator for the national Emergency Operation Center for Polio in Pakistan.

But Raza says even one refusal is a potential risk because a child could have the virus without displaying symptoms and spread it through the sewage system.

Interviews with health workers and parents suggest that even though refusal rates are low, they appear to be underreported.

Safdar says one of the biggest challenges is that people advocate against vaccines on social media.

"Whenever something is posted which is negative against the program or against the vaccination, it gets viral", he says. Even material prepared by Western anti-vaccination activists is spread around in Pakistan.

In March, three children died in Nawabshah, a city in Pakistan's hinterlands. Raza says the children died after receiving an expired measles vaccine.

In the days after the report of the measles story, thousands of parents refused the polio vaccine. *"That really derailed the whole process of measles vaccination – and of vaccinations in general"*, Raza says. For the most part, though, parents oblige.

Dealing With Danger

Before the two young women were attacked, Nida and Sahar marched through the Fauji slum, armed with clipboards and a cooler box of polio vaccine, banging confidently on flimsy doors. At one, a woman answered, smiling. She rounded up her children, who were chasing a chicken that quickly scurried under a day bed in the living room. One little girl, Jannat-Noor, refused to open her mouth. *"Come on, it's sweet"*, Nida purred. *"Bravo!"*

Jannat-Noor burst into tears. Nida colored Jannat-Noor's finger with a sharpie to indicate she'd been vaccinated. *"It's nail polish"*, she said smiling.

Once finished, the women chalked notes on the wall outside — notes for the next vaccination team. Nida and Sahar estimated they earned $16 for five days work like this.

(cont'd P16)

Why It's So Hard To Wipe Out Polio *(cont'd from P15)*

It is not a lot of money. *"We serve community — that's why we feel happy",* Nida said.

But after the attack on Nida and Sahar, another health worker looks grim. He's just watched Nida burst into the health center. *"I am very much concerned about my security",* says Dilbar Khan, from the World Health Organization, who oversees polio vaccination in this area. *"We have families. We have children. We are as concerned about these front-line polio workers as we are for ourselves."*

For a few tense minutes, the health workers aren't sure if the attacker will follow the women to the center. Police arrive to take details.

As for Nida, somebody has bandaged her head. She lies on a gurney. I ask her if she's still willing to work as a vaccinator. She shakes her head — no. That refusal, of a health worker to go back to the front line, also chips away at Pakistan's ambitious goal of zero.

With additional reporting by freelance reporter Hina Javed in Karachi. ⬢

Link to full article here.

A Pakistani health worker administers the oral polio vaccine to a child during a campaign in Karachi on May 7. Because of past attacks on vaccinators, security personnel are often assigned to accompany them: Rizwan Tabassum/AFP/Getty Images