



**POLIO NSW**

*formerly Post-Polio Network (NSW)*

# NETWORK NEWS



*Incorporating – Polio Oz News*

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**Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS**

## Country Conference 2018



**Panthers Port Macquarie**  
([www.portmacquarie.panthers.com.au](http://www.portmacquarie.panthers.com.au))

1 Bay Street, Port Macquarie

Cost: \$35.00

**Informal Conference Dinner:**  
Friday, 21<sup>st</sup> September, 2018, 6.30pm

**Conference Program:**  
Saturday, 22<sup>nd</sup> 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](http://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 14<sup>th</sup> 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 11<sup>th</sup> 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](mailto:info@post-polio.org)  
See other questions at [www.post-polio.org/edu/askdrmay.html](http://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](http://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<sup>1</sup> 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<sup>2</sup>. More recently an MRI study on a child with acute wild polio in India documented changes in the SN.<sup>3</sup> 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.<sup>3</sup>

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](http://www.post-polio.org)>*

## **[www.polioplac.org](http://www.polioplac.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.polioplac.org](http://www.polioplac.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 Jacqueline 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

The screenshot shows the Polio Place website interface. At the top right is a search bar. Below it is a vertical sidebar with links: Home, People, History, Resources, Post-Polio Directory, Articles from Post-Polio Health, PHI-Funded Research, Medical Articles, and a link to the 'Living With Polio' section. The main content area has a yellow header 'Living With Polio'. Below it is a text block about millions of individuals living with polio, mentioning nerve damage and challenges. There's a sidebar for 'Advice, hints, explanations, etc.' and a reminder about IVUN news. At the bottom is a 'Category' dropdown menu with 'Apply' and a list of topics including accessibility, activities of daily living, assistive devices, audiology, communication, etc.

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.”

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.

The screenshot shows the homepage of polioplace, a service of Post-Polio Health International. The main navigation menu includes Home, People, History, Resources, Post-Polio Directory, Articles from Post-Polio Health, PHI-Funded Research, Medical Articles, and Living With Polio. The 'Articles from Post-Polio Health' section is highlighted. It features a search bar and links to 'Past Issues of Post-Polio Health®' and 'Listed by Topic'. Below this, there's a list of articles with titles like 'Aging with Polio', 'A Tribute to My Mother', 'Aging in place with a Disability', 'Let's Clink Our Champagne Glasses!', 'Celia Yoder Looks Toward 95th Birthday', and 'Aging Well with Post-Polio Syndrome: The Weight of the Matter'. A sidebar on the right lists 'Post-Polio Experts Present' and provides language selection and dark mode options.

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](http://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.

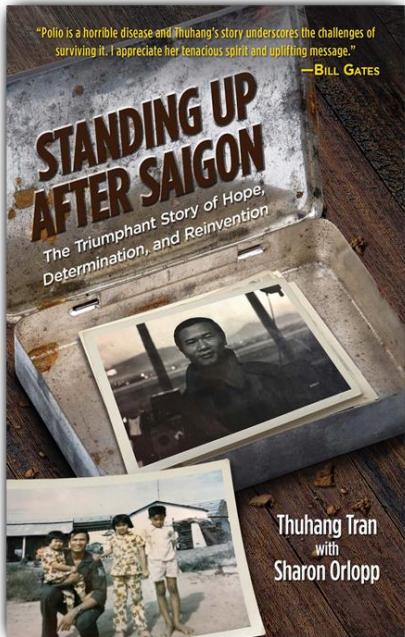
On the morning of April 30, we crawled out of the ham when we hadn't heard any artillery chatter from the M-16s and AK-47s or any overhead screaming rockets for several hours. We quickly used the bathroom and began searching for scraps of food in the kitchen. We shared some dried instant noodles, a stale 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/gEyGAWioSrl](https://youtu.be/gEyGAWioSrl)> or visit <[www.StandingUpAfterSaigon.com](http://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.



66 Rosamond Street  
Hornsby NSW 2077  
[<www.mtwilgaprivate.com.au>](http://www.mtwilgaprivate.com.au)

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:

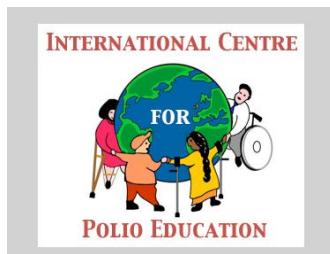
- How to use the Consumers Health Forum Storycards  
[<chf.org.au/sites/default/files/codeine-project-pdf.pdf>](http://chf.org.au/sites/default/files/codeine-project-pdf.pdf)
- Storycards at A4 size  
[<chf.org.au/sites/default/files/codeine-project-cards-a4.pdf>](http://chf.org.au/sites/default/files/codeine-project-cards-a4.pdf)
- Storycards at DL size  
[<chf.org.au/sites/default/files/codeine-project-cards-dl.pdf>](http://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>](http://chf.org.au/sites/default/files/codeine-project-slides.pdf)

Resources:

-  [codeine-project-pdf.pdf](http://chf.org.au/sites/default/files/codeine-project-pdf.pdf) (3.05 MB)
-  [codeine-project-slides.pdf](http://chf.org.au/sites/default/files/codeine-project-slides.pdf) (3.6 MB)
-  [codeine-project-cards-a4.pdf](http://chf.org.au/sites/default/files/codeine-project-cards-a4.pdf) (3.39 MB)
-  [codeine-project-cards-dl.pdf](http://chf.org.au/sites/default/files/codeine-project-cards-dl.pdf) (3.54 MB)

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



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<sup>1</sup>. 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<sup>2</sup>;
- 2) Slowed performance on the most difficult tests of attention and information processing speed were associated with lower scores on word finding tests<sup>3</sup>;
- 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<sup>4</sup>.
- 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<sup>5</sup>. 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<sup>1-4</sup>. 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.

## REFERENCES

1. Bruno, R.L., et al. (1991). Polioencephalitis, stress and the etiology of Post-Polio Sequelae. Orthopedics; 14: 1269-1276.
2. Bruno, R.L., Zimmerman, J.R. (2000). Word finding difficulty as a Post-Polio Sequelae. American Journal of Physical Medicine and Rehabilitation; 79: 343-348.
3. Bruno, R.L., et al. (1995). The pathophysiology of a central cause of postpolio fatigue. Annals of the New York Academy of Sciences; 753: 257-275.
4. Bruno, R.L., et al. (1996). Polioencephalitis and the Brain Fatigue Generator model of post-viral fatigue syndromes. Journal of Chronic Fatigue Syndrome; 2: 5-27.
5. Mayuex, R., Matison, R., & Rosen, J. (1981). Tip-of-the tongue anomia in Parkinson’s Disease. Neurology; 31: 102.

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

Source: <[www.stuff.co.nz](http://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



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.

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."*

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# 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)



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](http://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](http://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](http://www.nbnco.com.au)>

### **Telecommunications Industry Ombudsman**

**Freecall:** 1800 062 058

**Website:** <[www.tio.gov.au](http://www.tio.gov.au)>



# 2018 Polio Program Activities

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

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Have you added your details to the Australian Polio Register?  
[www.australianpolioregister.org.au](http://www.australianpolioregister.org.au)