



## 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.

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)



#### 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

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“**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 LEO 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](mailto: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.

## 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. 🌟

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



**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](http://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



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## 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](http://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 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.

[Read More](#)



#### Walk With Me

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

[Read More](#)



#### 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](http://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](http://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](#). 🌐

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## 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



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

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.

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 inevitably 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 annals 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."* ●

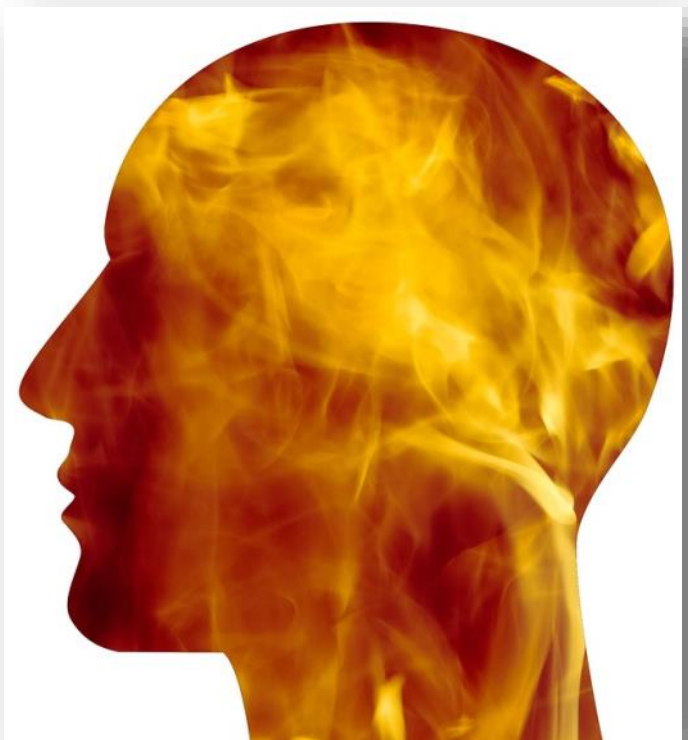
## Our Perception Of Pain

**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 ourselves!

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.

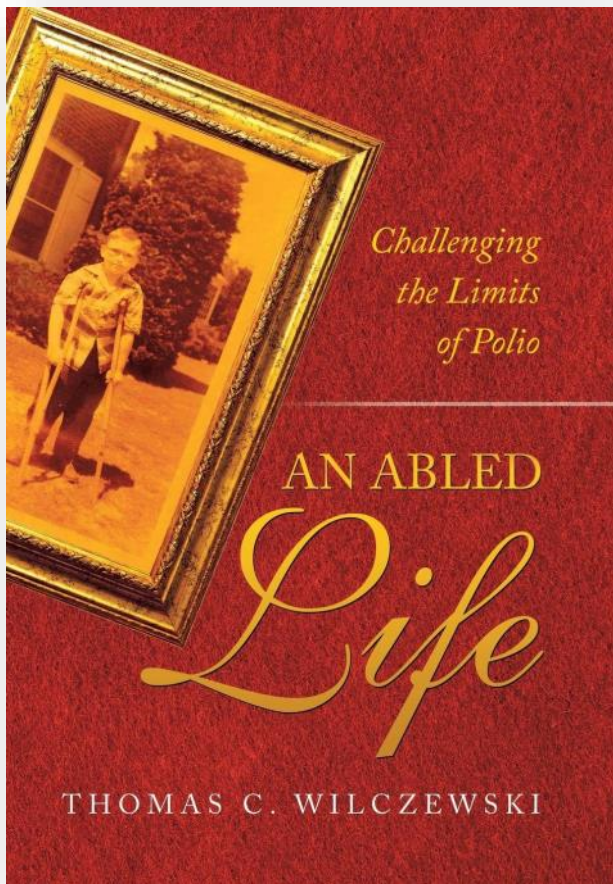
The concept of pacing is one of the most effective strategies to increase our capacity. Once you have your times for activities, or overall amount for a day, you can start increasing what you do. Again, we want to start with one thing and slowly increase the time and not let pain guide us. Often, the 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](http://www.kickstarter.com/projects/1146763627/a-pound-of-kindness-childrens-book)



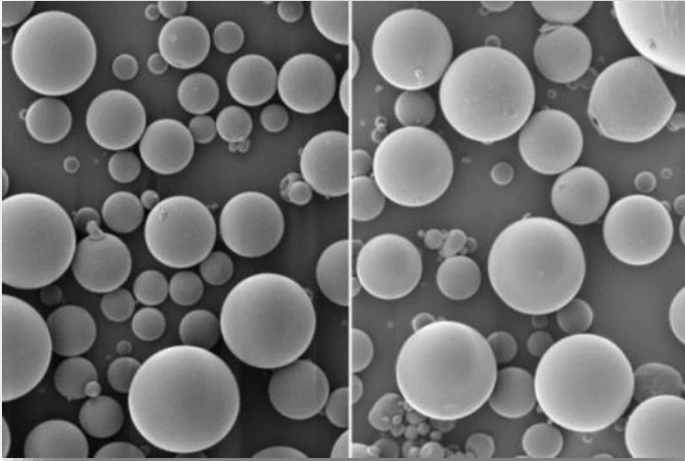
[Facebook version](#)

[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.



**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.

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

*Credit: Courtesy of the researchers*

### 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.

## 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](http://www.sciencedaily.com/releases/2018/05/180521154250.htm) ●

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

By Daa Hadid

Source: [www.npr.org](http://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 Noshewan 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*

## Polio This Week

**Source:** [Polio Global Eradication Initiative](#) — as of Wednesday 29 May 2018

A vaccine manufacturer in Stockholm has taken the first step towards becoming a certified Poliovirus Essential Facility (PEF), leading the charge in global efforts to safely and securely contain type-2 poliovirus. This facility has been awarded a Certificate of Participation co-signed by the National Authority for Containment (NAC) in Sweden and the Global Commission for the Certification of Poliomyelitis Eradication (GCC). The Certificate is the first of its kind to be issued, indicating formal engagement in the global containment certification process.

Wild poliovirus type-2 was declared eradicated by the GCC in September 2015, however, there is risk of the virus resurging. Following the removal of the type-2 component from oral polio vaccine (OPV) and the discontinuation of type-2 containing OPV from routine use in April 2016, countries around the world have been asked to safely and securely destroy their type-2 polio samples. As a further precaution, countries continue to immunize against type 2 polioviruses with inactivated polio vaccine. For facilities needing to retain the virus for vaccine production or for critical research, stringent containment measures need to be followed. The first step is getting a Certificate of Participation.🌐

### Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

Total cases	Year-to-date 2018		Year-to-date 2017		Total in 2017	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	8	5	5	4	22	96
—In Endemic Countries	8	1	5	0	22	0
—In Non-Endemic Countries	0	4	0	4	0	96

### Case breakdown by country

Countries	Year-to-date 2018		Year-to-date 2017		Total in 2017		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Afghanistan	7	0	3	0	14	0	3 Mar 2018	N/A
Democratic Republic Of The Congo	0	4	0	4	0	22	N/A	19 Feb 2018
Nigeria		1	0	0	0	0	N/A	15 Apr 2018
Pakistan	1	0	2	0	8	0	8 Mar 2018	N/A
Syrian Arab Republic	0	0	0	0	0	74	N/A	21 Sep 2017



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



## Polio NZ Retreat

Anyone planning to head 'over the ditch' in October might be interested in attending the Polio NZ Retreat and AGM from Friday 5th to Sunday 7th October — one week before Polio Australia's Retreat in Adelaide! A bit of friendly rivalry, perhaps? Of course, we are always happy to support our Kiwi cousins. For more information, email: [secretary@polio.org.nz](mailto:secretary@polio.org.nz).



### Polio NZ Inc 2018 Retreat

Queen Elizabeth Wellness and Spa, Rotorua  
Friday 05, Saturday 06 and Sunday 07 October 2018  
**Expression of Interest Only**

Polio New Zealand will be facilitating its 3-day Retreat for Polio Survivors and their partners/family members from Friday 5th, to Sunday 7th October 2018

This is our 4<sup>th</sup> annual gathering, which includes the AGM. The Retreat may include sessions such as:

- Interactive group sessions and consultation opportunities with a variety of allied health professionals
- Hydrotherapy available throughout the day and morning exercises. Latest orthotics, aids and equipment displays and discussions, Seated Meditation Sessions
- Activities and fun to keep our minds active, Creative Workshops
- Massage therapy

#### **POLIO NZ INC Retreat & AGM 2018**

**Friday 05, Saturday 06 and Sunday 07 October 2018**

Approx. cost of registration fees for 2 nights accomm, all meals and most activities, \$**250** pp

Numbers will be limited to 50, and the available beds will be allocated on a first in basis.

All fees yet to be confirmed. There will be an opportunity to apply for financial assistance if necessary.

Please provide me with more information about the Polio Retreat & AGM when available.

Name:

Address:

Phone/s:

Email:

**Return to:** Polio NZ Retreat & AGM, Polio New Zealand Inc  
PO Box 791, Taranaki Mail Centre, New Plymouth, 4340, New Zealand  
Email the form to: [secretary@polio.org.nz](mailto:secretary@polio.org.nz)