



Polio NZ Inc

# POLIO NEWS

July 2015



## Retreat Going Forward



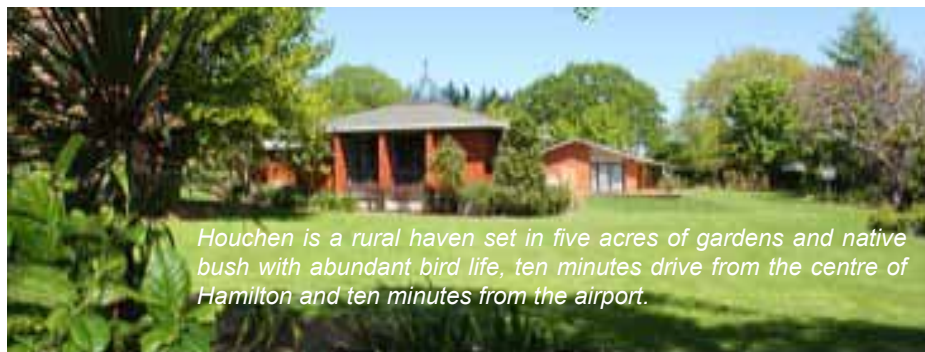
*One of the goals set by conference last year and adopted by the Board as part of its Strategic Plan was to start holding retreats along the Australian model. Board member Sue Griffin has taken responsibility for this considerable task, and organised the first, at Houchen Retreat House and Conference Centre, just outside Hamilton, in August.*

Houchen's existence owes much to one family's generosity, much like the Wilson and Duncan philanthropy. We should feel right at home there, and it's wheelchair friendly throughout.

Houchen is an ideal location to revitalize the spirit in the serenity of the spacious grounds, enjoying a programme that includes interesting speakers and some fun presentations plus the company of others who have survived polio.

Registration and orientation starts at noon on Thursday 6 August with a powhiri at 2.00pm. The programme then runs through to midday Sunday, ending with a light lunch.

Registration (\$126.50) includes four days of retreat, and all meals. Accommodation is extra for those staying in (\$45 per night). Places were snapped up through information sent to groups, but at publication deadline cancellations left three bed spaces still available. Sue's contact details for further information are on p.2.



*Houchen is a rural haven set in five acres of gardens and native bush with abundant bird life, ten minutes drive from the centre of Hamilton and ten minutes from the airport.*

### Not just a personal benefit

Retreat facilitator Sue points out the knowledge gained during this Retreat won't just assist participants to better manage their own conditions. Through sharing what they learn with their own health professionals, they will hopefully facilitate improved care for other patients presenting with the Late Effects of Polio.

Come ready to contribute to the Retreat's success to ensure it becomes an annual event.

The regular monthly meeting of the Polio NZ Board at Houchen Retreat Centre on Saturday 8 August at 4pm is open to all members.



*Houchen's garden pleasures include a unique labyrinth, based on the classical Cretan design, but adapted to its sloping hilltop location. It can be enjoyed just as a delight to the eye, or more actively – and there's even flaming torches on offer to illuminate the site at night.*

# Polio NZ Inc

## About Us

Polio NZ is an incorporated society dedicated to seeking support for people who have had poliomyelitis. It does this through information sharing and where possible, assistance to polio society members and their families, whether or not they are experiencing problems at present.

The Society's Board of Management meets regularly either in person or by teleconference, and the annual general meeting of members is usually held in September or October.

Polio News is published three times a year (usually April, July and November) and sent to all members.

Contributions are welcome and the deadline for copy is the 15th of the month before publication.

Disclaimers: Opinions expressed in the newsletter are those of the writers and not necessarily those of the Society. This Newsletter is not intended to provide medical advice. For decisions about health matters, first consult your health professional.

Similarly, no brand name product mentioned in this newsletter has any formal endorsement by Polio NZ.

### Acknowledgement:

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*"When you start doubting yourself, remember how far you have come. Remember everything you have faced, all the battles you have won, and all the fears you have overcome."*

### ***Last minute regional report...***

#### ***Hawkes Bay***

Ten polio survivors and friends attended a lunch on 15 June and despite the cold, had an enjoyable time. John Carver formerly of Christchurch talked on being a polio spouse. John supports spouses getting all the information available on the late effects of polio; attending doctor's appointments and all the while keeping a positive attitude at home.

# From the President

## ***A WEEKEND IN TORQUAY.....***

### ***with NO Faulty Towers***

#### **President Barry reports on the experience of the 2015 Polio Australia Health and Wellness Retreat.**

It was impossible to fault anything about the organisation of this retreat. The venue was a resort

hotel in Torquay, out on the coast from Geelong, about an hour and a half from Melbourne. It was a sprawling resort, very easy to move around in for Polios with any degree of disability.

I went to this retreat at the end of April with Polio NZ Treasurer Diane Mathews and we both agreed it was most informative, interesting and, all-in-all, most enjoyable.

The programme over the three days was very extensive with a comprehensive list of experts talking about the many health issues that can affect those of us enduring the late effects of polio; issues like breathing, orthotics, pain and fatigue.

There were experts on senior rehabilitation, naturopathy and healthy eating. An exercise physiologist gave us an insightful awareness of changes to exercise appraisal. There was an audiologist from the National Hearing Centre, a psychologist who talked about self-compassion, a pharmacist about using medicine wisely and a movement specialist on ways to improve functional movement. They even had a session specifically for partners of Polios.

On the Saturday the organisers refreshed the programme and had lessons on cryptic crosswords, creative writing, exploring the sharemarket and the Japanese floral art of Ikebana.



*Spot Pres Barry very attentive at a Retreat session.*

To close off the three days there was yoga, mindfulness meditation, worship through music and a session on philosophy.

If all this sounds a little too much, it wasn't really, because you weren't all in the same room for the whole day. You could choose to go to whatever session you wanted, so you could take time out if you liked and every day after lunch there was a rest hour. The experts also held private one-on-one sessions.

Looking back, after this experience I'd recommend retreats for all Polios. It's a time to not only hear from the professionals, but also to put your questions to them. It's a time to hear the latest on post-polio management, to check if there are any new resources in this country, to reinforce the positives in your situation and to hear anecdotes and ideas from your fellow Polios and share experiences, to maybe get some inspiration from how others have coped with managing the late effects of polio.

Meanwhile, I'll hopefully see at least some of you at the New Zealand retreat in Hamilton on August 6th.

'Til then, stay healthy.

Barry Holland  
President,  
Polio NZ Inc



Children playing in Pakistan. On 11 August it will be a full year since a case has been found in West Africa, leaving the Pakistan-Afghanistan strain the world's last.

Politics, propaganda and terrorism complicate a last battlefield in the fight to eliminate polio, writes health reporter Donald G McNeil in the NY Times in his review of a new documentary "Every Last Child". His analysis sheds light on events in a region impacting on New Zealand for more than the battle against polio.

Everyone in it is fighting a holy war, he says. *It's the vaccinators against the virus, the Taliban against the vaccinators, the police against the Taliban. Above them, outside the frame, is a dark tornado of greater forces: radical Islam versus those it considers Crusaders, the CIA's actions versus those of the WHO, Western science versus Eastern faith. Every time it touches down in the slums of Karachi and Peshawar, it leaves behind new victims: dead vaccinators and paralyzed children.*

While the visual imagery conveys the splendour and terror in ways that prints can't, he sees the film struggling to explain the core of the crisis. *Why would anyone decline a gift with no strings attached – a gift that, rejected, could consign one's own children to paralysis?*

*Even worse: Who would ruthlessly gun down women and girls – neighbors and clansmen, not strangers – who are the innocent bearers of that gift?*

*The film offers hints: the tired but still potent rumors: That the vaccine is really birth control aimed at Muslims. It comes from the same American skunk works that brewed up the virus causing AIDS and shipped it to Africa.*

*Left unexplained is why this blind rejection stays nailed solidly into a few tiny pockets of the*

*Islamic world while the vast majority of Muslims accept the vaccine – and other Western drugs.*

The answer is complicated, he says. *As polio has been driven back into its last redoubts, it has become more and more a disease of the aggrieved minority, of people so beaten down that they trust nothing offered by outsiders – and for whom almost everyone is an outsider.*

And worse – an outsider who brings the disease in the first place. Such fears also complicate dealing with Ebola and AIDS in rural Africa.

*For a decade, polio has been essentially a Muslim disease. The 2005 hajj season spread a Nigerian strain to Mecca and out from there. But most Muslim countries clamped down hard. Saudi Arabia, for example, vaccinates pilgrims on arrival.*

The virus now hits almost only the most conservative, remote people who have fought for generations to retain their identity. People we might recognise in the Scottish Highland spirit.

*This is not to romanticize them. The Taliban is to the Pashtuns roughly what the Cosa Nostra once was to Italian-Americans: a mix of criminal gang and self-defense group, religiously conservative and quick to violence.*

There's even a parallel in the behaviour of a Mafia forerunner, issuing death threats to health officials during a 1916 Brooklyn polio outbreak.

*The CIA's use of vaccinators to hunt Osama bin Laden was a disaster for the polio campaign, and military drone strikes, virtually all in Pashtun territory, have increased Pashtuns' fear that the world and the Pakistani elite is against them. They have grievances: Urbane Pakistanis talk about them the way American snobs refer to "hillbillies" and "trailer trash."*

But since the film was shot in early 2014 there has been change and polio cases are dropping.

Some legitimate complaints, like being offered nothing but polio vaccine, are being addressed with services like pop-up pediatric clinics where children receive checkups, vitamins, deworming drugs, antibiotics and several vaccines.

Plus efforts by the Pakistani Army to assert government control of areas where vaccine resistance was strongest have helped.

The day of the last child appears to be getting closer, he concludes.

See the Polio NZ Facebook page for the link to the full text of this review, or search "nytimes + Every Last Child." •



## Strategy progress

### Orthotics survey:

A pilot survey has been run in Christchurch and results are being compiled. Thanks everyone who took the time to complete – and to return it!

**Clinic:** Board members continue to work toward establishing a late effects clinic for polio survivors. It is not going to be a rapid development but the Board are up-beat and optimistic with activities so far. Members of the working group are concentrating on making valuable links with professionals and academics across the country, discussing Polio NZ Inc.'s aims and enlisting support, information and further leads. The momentum is building with every meeting as we work toward a bottom-up approach which it is envisaged, will eventually result in a pilot followed by an evidence-based proposal to funders and policy makers. A full report of activities will be presented at the AGM.

### We're Still Here Campaign

Planning continues for gathering on the steps of Parliament at noon on Wednesday 21 October. More information to come.

**Retreat:** As reported on p.1 it's all up and go. Hopefully to become an annual event.

**Communications:** Unfortunately the website is a bit out of date at the moment as the techies work out how to shift platforms. If this sounds like shunting trains then yes the analogy is appropriate. To mix metaphors, so is the concept of getting ducks in a row. And for good measure, to throw in another cliché, good things take a little time. Watch this space.

**Walk With Me:** Despite enthusiasm for the Walk With Me campaign, including from likely partners, the board has decided it would be wise not to pursue too many initiatives at once, and to leave this over to next year. •



# POLIO NZ INC.



## NOTICE OF ANNUAL GENERAL MEETING

The Thorndon Hotel Wellington  
(formerly the Kingsgate)

Wednesday 21 OCTOBER 2015 at 9.30am

### AGENDA

1. Welcome by Chair
2. Apologies
3. Minutes of previous AGM and matters arising
4. Annual Report, including Financial Report
5. Election of Board of Management Members
6. Proposed changes to the Constitution
7. Motions
8. Any other business

### 7.0 Nomination of Board of Management Members

7.1 Nominations for Board of Management Members shall be called for at least 28 days before an Annual General Meeting.

Each candidate shall be proposed and seconded in writing by Members and the completed nomination delivered to the Secretary.

Such nomination shall include a brief biographical summary of the nominee citing information relevant to the role for which they are nominated, and the length of such summary shall not exceed one side of an A4 sheet of paper per Nominee.

Nominations shall close at 5pm on the day one week before the Annual General Meeting. In the event that no nominations for an office are received prior to an Annual General Meeting then nominations may be taken at the Annual General Meeting from the floor. •

## News briefs

**In respectful recognition:** With sadness Polio NZ learned of the sudden passing of Iris Wilson, wife of Ray Wilson, Polio NZ President for over a decade. Iris is remembered fondly by older members as a lovely caring and supportive woman whose friendly nature meant she got on well with others. Despite considerable health issues over the years there is no doubt her support greatly aided Ray during his years as President. Polio NZ has lost a loyal supporter and she will be greatly missed particularly by members in the mid to lower South Island. May she rest in peace. •

**Best recuperative wishes** to Patron David Duncan who has had major surgery that has temporarily had him in a wheelchair. David and his family have already more than adequately demonstrated their empathy with disability, so we're sorry they're having this added personal experience and hope David will be fully mobile again soon. •

**Congratulations to Dave Hill**, husband of Polio NZ member and high-achieving athlete Trish Hill, who deservedly appeared in the Queens Birthday Honours List for services to Paralympic sport and health.

After a lifetime of helping other people with their disabilities, Dave now has his own challenges with Superficial Siderosis (SS) a rare and complex neurological condition. He runs a website and writes a blog, connecting and informing a worldwide network of people who would otherwise be very isolated because of the rarity of the condition.

Dave writes very black humour of challenges that many will identify with. Like falls. It's well worth checking out, even as a reminder that there's many out there with needs that parallel those of polio people.

<https://superficialsiderosis.wordpress.com/> •

**A website for health professionals** launched by Polio Australia at [www.poliohealth.org.au](http://www.poliohealth.org.au) provides specific post-polio information including the 2016 Australasia-Pacific Post-Polio Conference, professional development workshops, videos and other resources, clinical practice and other publications, research, plus the Australian Polio Register. •

**Treasurer Diane Mathews** adds to President Barry's report of the 2015 Polio Australia Health and Wellness Retreat.

*I'd like to thank all of you for sending me to this Retreat. As always, it was great to be with other polio survivors who are faced with similar challenges, obstacles and bodies which are running close to their 'use by' date. I always learn as much from others attending as I do from the presenters.*



*The resort at Torquay was a good place to stay and mostly accessible. I was very fortunate to be allocated a room fairly close to the rooms we were using during the day and at the front of the buildings with a balcony and view out over the sea. Very spoiled.*

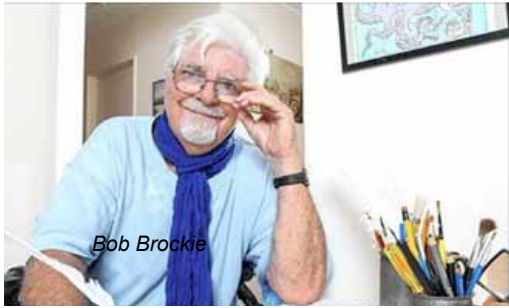
*The presenters were very good and covered their topics well. All were happy to take questions as they went along which made for a relaxed atmosphere. I felt comfortable in asking the 'daft' question that I thought was mine alone only to find that seven other folk wanted to know the same thing.*

*Thank you all again. I've returned with renewed enthusiasm and found the break away from the humdrum really energising.* •

**Nelson CCS Disability Action** celebrated its 80th anniversary in April with a timeline presenting its history. Those present at its opening included Rex Wastney (Polio 1949 aged 11 years), Pauline Withington (Polio 1951/2 aged 25 years) and Brian Robinson (Polio 1949 aged 17 months). Rex and Brian were both members of the original Nelson Crippled Children's Society. •



*Rex Wastney of Nelsons polio support group and Nelson Rotary President Jan Aberhart at the opening of the panels*



Bob Brockie

**‘The Brockie Horror Show’** feature story about scientist/cartoonist

Bob Brockie in The Listener April 11-17 refers to his polio experience as an adult in Sicily – and its return in later life. Fittingly for a scientist who studies hedgehogs, Bob Brockie turns out finely barbed cartoons. •

**Tui Mayo** of Dunedin featured in the Otago Daily Times when she turned 100 in May:

“The polio could not get her, she has survived being hit by a car, led a life of travel and adventure, and awaits her letter of congratulations from the Queen. The secret to a long life: eating well and keeping her mind sharp by reading.” •



Dennis Hughes

**Cycling to end polio:** Dennis Murdoch is a 67-year-old road cyclist from Huntly and also president of Huntly Rotary. All through June he was cycling across Europe to raise funds for the End Polio Now Campaign.

That’s 1,714km through six countries, starting in Prague in the Czech Republic, and ending in Passau, Germany – with a good cold beer by the look of his Facebook page. Dennis will be speaking at the Retreat in Hamilton. •

**Hawkes Bay Polio Star**

Harry Mills, a recent new member of the Hawkes Bay Polio Support Group, will be appearing (along with his wheelchair by the look of the photo) in Roger Hall’s play, ‘Who Wants be 100?’ opening in Dannevirke 23 July. •



Harry Mills

**All Walks of Life:** To celebrate 21 years of existence the Bayside Polio Group in Victoria teamed up with a local Rotary Club and a film company to produce a 15-minute film about polio and the lives of some people managing its late effects. The brief was to communicate polio, peer support and hope through 14 interviewees. Like community worker Shirley Glance who for years told people her disability was a Boer War injury, but now talks about the ‘advantages’ of her polio experience in what she has accomplished. “This has made me who I am.”

Likewise social worker Dr Margaret Cooper who has used her own experience of disability to



Dr Margaret Cooper.

work as an advocate for others.

Science teacher and climatologist Jack Harrison tells how a hospital staff member brought books to relieve his solitary boredom. Grabbed at random from a library shelf, they were all physics and maths, which he consumed avidly – the joy of being switched on to science lights up his face. “I don’t see how anyone can be bored.”

Bookseller and volunteer Peter Willcocks describes his childhood as offering “all sorts of wonderful things” as people opened special doors for a disabled child. His sunny attitude continues (despite a cheerful admission of having accelerated his decline through doing too much) as he describes how much freedom he has been able to achieve through using aids and equipment “in a healthy way.”

The interviewees are equally positive about the benefits of joining a support group, even public servant Brian Caulfield who says he resisted joining “I didn’t want to be with those disabled people” He had learned, and been able to help others too. For him PP stood for Polio Positive.

“If we didn’t become positive we’d be left behind.”

The film is available on the Polio Australia website. •



Peter Willcocks

## Retreat Facilitator Sue We acknowledge you!

*Polio NZ Board member Sue Griffin from Hamilton, born Wellington 1947; contracted polio 1948; educated at Karori, Plimmerton, New Plymouth and Massey University is the first subject of a series of profiles by Penny Humphreys.*

### What are you doing currently Sue?

‘I am a rather over-extended volunteer for Polio NZ, a Grandma and convert to self-preservation!’

### What would you rather be doing?

‘I’d rather be designing eco-residential structures that are functional, iconic and memorable. But realistically, pretty much what I am doing, with less exercise and pain!’

### What memories stand out from before polio?

‘I was so young - so no real memories. I remember physical therapy from a young age.’

### How was school and do you still know anyone from then?

‘School was ok, as I had five older siblings, and one was head prefect. I hated sports day, but didn’t have many problems with peers. I have two friends from High School I still see frequently.’



*Sue Griffin at Waikato Post Polio Group's information stand at a wellbeing expo.*

**How have you made a living? Has this been effected by polio?** I was a Registered General Nurse, specializing in trauma and emergency medicine. I did eventually have to leave because of deteriorating function due to LEOP.

**What are the most useful skills you learnt from having polio in your life?** I think it taught me resourcefulness, being good at adapting to difficult situations. I was known as a problem solver, which I feel comes from having to find ways around things in order to accomplish tasks’.

### Do you feel polio has affected relationships with others?

‘The psychological effects are an unknown minefield. I do believe subconsciously, it has caused me to be reserved and led to difficulty in relationships’.

### Do you feel differently about yourself now from how you felt when you were younger?

‘As a child, the concept of having had polio did not bother me too much, but I now worry about exponentially diminishing function in my daily life. Is that polio or just failure to accept getting older?’

### How do you fit into your whanau, hahi/church and wider community?

‘My whanau accepts me as I am with my older siblings always having been somewhat protective.’ •

## Gratitude Corner It's good for your health

Be grateful at this time of year that you can look out of a dry house window at all that rain/snow – Sandy Stevens

What are you grateful for? This space welcomes suggestions.



### Wilson Home people:

Weekly Review no. 348 (1948) will be of interest to you. <http://tinyurl.com/phwfrax>

This is from ArchivesNZ, which offers hours of nostalgic entertainment





## EDITORIAL HIGH HORSE

How time flies when preparing this newsletter and what wonderful things I learn through grasshopper insights from on line research.

Like five things promised from giving up processed sugar (improved energy, stable weight, more efficient digestion, no sugar cravings and healthier skin).

Hop from there to how Italian diners can have a dinner in the dark experience with the help of blind waiters. This at an 'ethical hotel' mostly staffed by people with Down Syndrome.

Jump from there to debate over a new non-intrusive in-utero test for Down Syndrome that could lead to the extinction of DS people (already a stated goal in some countries).

This raised the spectre of eugenics and a hop to wondering how polio people fared under Nazi euthenasia of mental and physical defectives.

Just an initial foray into that (Anyone want to write us a story?) led somehow to debate on how President Roosevelt should be represented in a 1990 memorial. With minimal sign of his disability, as he chose to present himself, or in a wheelchair? Disability activists claimed it would be hypocrisy if he were not, given his choice was governed by the prejudices of his day – the pity and condescension – against disability.

The New York Times supported the eventual wheelchair option because of its silent witness to the irrelevance of disability to people's capacity to participate to the highest levels in society.

I spend a lot of time at the moment visiting rest homes to support family members with disabilities. Finding interesting internet items to share, especially with someone speech-impaired by stroke, offers ways to keep connections, even when shut away by the segregation of care

I'm so glad I have learned to hop around the internet before I get immobilised. Resthomes, should they exist at all, better all have connectivity by the time my generation arrives. Better still, if they take note now of initiatives reported on-line, like how introducing a preschool programme into a resthome changed the lives of both toddlers and residents. (Could have told them that.)

Meantime, when you've got a moment, or a handy grandchild willing to share their phone and some laughs – check out "Bored Panda". •

## ***Post Polio Wise Elders Find a Gain for Every Loss***

"How do we thrive in the midst of heartbreaking loss? How do we grieve well and then let go and forge ahead with grace and hope? It is not easy. But it is possible."

So writes the wonderfully named Sunny Roller, educator, researcher and member of Post-Polio Health International Board of Directors.

Sunny writes a blog defined as 'the art of living well as we grow into later life with the effects of polio' that's well worth following if you can.

Here she is on loss (or grief).

"The only way I have been able to move forward after a life loss has been first, to cry my guts out and acknowledge my sorrow. Over and over. Then, when I am ready, and sick of being so sad, I work to reinvent a new reality and perception of my life. I look hard for some fresh gain in the aftermath of that debilitating loss. It can be a large gain or a small gain. Doesn't matter. Just some gain. I work to reinvent my reality because I absolutely refuse to get stuck in the devastation which loss has the power to create, if we let it. Stomp! Stomp! That is not where I want to live every day."

In 2007 Sunny undertook a national study of 'post-polio wise elders' all of them with complicated physical disabilities from polio, and says these role models for successful late life adaptation with a disability taught her about reconciling losses.

All said adapting to loss had been a major life challenge, now with age-related issues as well as polio losses, social as well as physical change.

Yet many of them agreed that, in spite of new functional losses, life was somehow better than when they were younger and physically stronger.

They began to transform their losses into opportunities for gain. Getting older brought new flexibility, despite constraints. They were more compassionate toward others than in their more competitive earlier years and changed perceptions of disability meant greater self-acceptance.

"These well-grounded role models teach us that on the heels of life's deeply felt losses, potential gains swirl all around us. It's not easy to see them at first, but as we invite them into view, and claim them one by one, it is possible to find the excitement in life again.

"In the process, we gotta ask for help and hugs," she writes. • ([www.sunnyrollerblog.com](http://www.sunnyrollerblog.com))



Californian orthotist Marmaduke Loke wants all orthotic users to be able to achieve the same ease and smoothness of walking that many people with amputation accomplish.

Loke is the pioneering clinician behind an innovative orthotic company, Dynamic

Bracing Solutions, which has developed a carbon-fiber, spring-loaded ankle foot orthosis (AFO) that has transformed the lives of many people, from wounded veterans to polio survivors.

He describes observing the amazing abilities of amputees with prosthetic limbs and hearing of people actually wanting amputation so they could improve their mobility. That's what he wants for them too – but without the extreme surgical measures!

Gait that is closer to normal translates into less energy expenditure and physical strain, enabling the patient to have a better quality of life both physically and psychologically.

Loke is well-versed in gait training. He began his career in a children's hospital, where he "gait-trained about 10 kids every day for several years," he says.

"When I entered the O&P field, I noticed a lack of orthotic education to enhance function of ambulation with lower-limb orthotics," he says. "Because of my experience, I had a good understanding of how the 'bio' and the 'mechanical' work together—the patient working with the device for better outcomes."

For the technically minded reader: Loke describes the main concept behind the DBS technologies as "true triplanar orthotic management."

"A skeleton comprises three dimensions, and we need to manage musculoskeletal structures in all three dimensions. Most AFOs – both custom and prefabricated – often only partially manage the sagittal and coronal planes. Very rarely is the transverse plane considered with traditional designs."

*This is the first in a series of profiles of some of the eminent Australian and international professionals on the conference programme as speakers and workshop presenters.*

Loke says he spends hours studying his patients, videotaping them before designing and fitting the graphite composite orthoses as well as during fitting and often during follow-up.

"I use a videotape of patients' gait to find out what their deficiencies are in each dimension and develop a walking solution to counter that, looking at issues such as balance, security, mobility, and alignment. It's very meticulous and time-consuming."

Functional activities of daily living rarely occur in one plane; therefore, motion can be described as triplanar or occurring in all three planes simultaneously.

"The ability to walk efficiently is based upon the proper alignment of the bones of the feet, which in turn affect the alignment of the ankles, knees, and hips," Loke notes on the DBS website ([www.dynamicbracingsolutions.net](http://www.dynamicbracingsolutions.net)).

"Muscle strength from above is also a factor. Weak or missing muscles create abnormal rotational patterns causing malalignment of the joints below. An effective brace must provide for triplanar control of the foot and ankle while providing triplanar support for weak muscles. It must work from the ground up and the top down simultaneously."

Some very potent before and after videos on the website show the transformative effects of the new technology. •

Thinking of going to Sydney? Keep an eye on the 2016 Australasia-Pacific Post-Polio Conference webpages: [www.poliohealth.org.au/conference-sydney-2016/](http://www.poliohealth.org.au/conference-sydney-2016/)

# Shaping of Polio experiences by family Christian worldview

Review by Gordon Jackman

A couple of weeks ago I had the pleasure of a visit by Mary Ellen Warren and her husband John. Besides both being polio survivors, Mary and I taught at Lytton High in Gisborne in the mid 1980s and it was great to catch up and have a very stimulating conversation.

Mary mentioned she had a copy of a thesis by Canadian Virginia S. Bodsworth exploring the effects of Catholicism and Protestantism on the lives of polio survivors. As someone who no longer practices the formal Christian faith I was brought up in, but nevertheless recognises that my world view was probably strongly influenced by the protestant religious framework of my childhood, I was keen to read it.

Most of the interviewees grew up in the post-war years when social conditions were very conservative, economic conditions were steadily improving, the polio vaccine was invented and the polio epidemics became a thing of the past in Canada as they did in New Zealand.

Many of the stories resonated with my own experiences. The description of Catholic and Protestant world views with regard to suffering, inequality and disability, gender and guilt, work and leisure was fascinating.

While always recognising that generalities never apply to everyone, after reading this thesis I now feel I can understand better some of the driving forces within me.

The first thing I noticed was how much my attitudes to and experience of polio matched that of Canadian Protestants. They saw polio as something to be overcome, and their parents were not fatalistic, overprotective or coddling, determined that their children who contracted polio were to be treated just the same as everybody else.

Protestants place a high value on individuality and productivity, and sometimes see illness and disability as contrary to God's plan for a perfect world. Protestant parents and communities promoted an ethos of equality by drawing attention away from the person's differences, by giving them the same freedoms as able-bodied children, by maintaining high expectations, by expecting them to do chores, and by including

them in the same activities as able-bodied children. Like them I was encouraged to be self sufficient and not to expect sympathy because of my disability.



*Everyone has a world view.*

Catholics tended to be more accepting of illness and disability because they saw it as a natural part of God's plan for an imperfect and flawed world. Catholic parents and communities were more likely to embrace inequality and give extra attention to the ill person long-term by offering extreme care, pity, protectiveness, lowering of expectations, excusing the ill person from chores, and excluding the ill child from participation in particular activities. Their behaviour highlighted the Catholic belief that a weak and vulnerable member of one's family is a special jewel to be cherished, and that looking after the poor and suffering is an opportunity to discover Christ in the sufferer and to welcome spiritual graces.

There seemed to be a relationship between religious worldviews and peoples' experiences in hospital with Catholics more easily accepting the authority of the medical profession while at the same time being generally more at peace with the world.

I find my own resistance to authority and accepting the limitations of the medical profession is more common in the Protestant tradition. However I also found that I shared the Catholic tradition of stoically never complaining, often not in one's best interest and to others' confusion, which makes me suspect that many of the behaviours I learnt as a child came not only from the religious worldviews but also society in general's collective worldviews towards disability.

I found reading this study a very interesting experience, bringing up many memories and seeing them from a new and interesting viewpoint, leaving me feeling a little more at peace with the world. There is so much in this study that I cannot hope to do it justice in a short review but I think all polio survivors would find something of interest whatever their faith or belief system now. The study can be found at <http://polioquebec.org/tips-and-resources/others-like-me>.

*Full title: Personal Experiences of Poliomyelitis through Diverse Christian Faith Worldviews in Mid-Twentieth Century Canada*

## Support Group News



Helen Cook with Bob and Jean Coe

**Waikato:** “Whew! What a mammoth 3 days at the Wellbeing Expo - Waikato Show. Thanks to all the members who came to help on our stand, handing out flyers and talking to people about Polio and Post Polio Syndrome. We gave out almost a thousand specially designed flyers, and made contact with several polios who didn’t know about our organisation. It was a great opportunity to reach out and touch our community. •

**Manawatu:** Questions came thick and fast at the Manawatu Post-polio Support Group’s lunch meeting in June – but that was expected.

Members had been invited to come seeking answers to any questions they might have about coping with the problems of post-polio syndrome. These were put in a question box administered by group leader, Raylee Murphy, who invited those present to pool their knowledge in the answers.

Lots of good information and books were exchanged and there was even some more lively entertainment as diners put their legs up on chairs to compare compression socks.

More than a dozen people came to Capers Café in Terrace End for the question time which is likely to prompt similar meetings later in the year.

Keen interest was displayed in ways to deal with pain and stress. There was also a sharing of information about developments at Queen Elizabeth Health in Rotorua, with several of the diners having been patients there in the past. •

## Polio NZ Facebook page ...



It’s a public page so we don’t know how many individuals are reading it, but those who have joined include many new and younger faces.

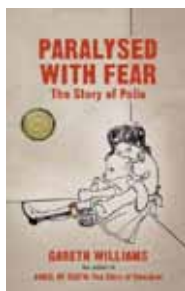
There’s great stuff there for discussion at group meetings. (Find somewhere with a big screen and internet-capable tv.)

Postings so far include stories of people who had polio (singer Joni Mitchell; violinist Itzhak Perlman; Steiff bear founder Margarete Steiff); stories of disabled young people today coping with their world; progress on polio eradication; bionic appliances; items from the Disabled Tourists Guide (wheelchair accessible airline toilets!!) and the world’s top accessible beaches.

The vehicle shown above related to a posting asking about powered swivel seats, which another member answered within the day. •

Can members please consider ‘promoting’ the site to their Facebook friends.

## Book review



**Paralysed with Fear** by Professor Gareth Williams (2013) is about much more than polio.

*“Williams has written a story about good and evil, successfully making poliovirus a villain in a gripping, multiact play... His book should be read by anyone interested in science, medicine, history, and public health. And by anyone interested in an incredible story told by a great storyteller.” – The Lancet*  
*“Williams is good on the terror [polio] inspired...and strongest of all is [his] highly entertaining description of the poisonous rivalry between scientists... His tale of vendetta and bitterness reminds us that even medical heroes can be as jealous and petty as the rest of us.” – The Times*

Now available in paperback or request your library to purchase it. •