

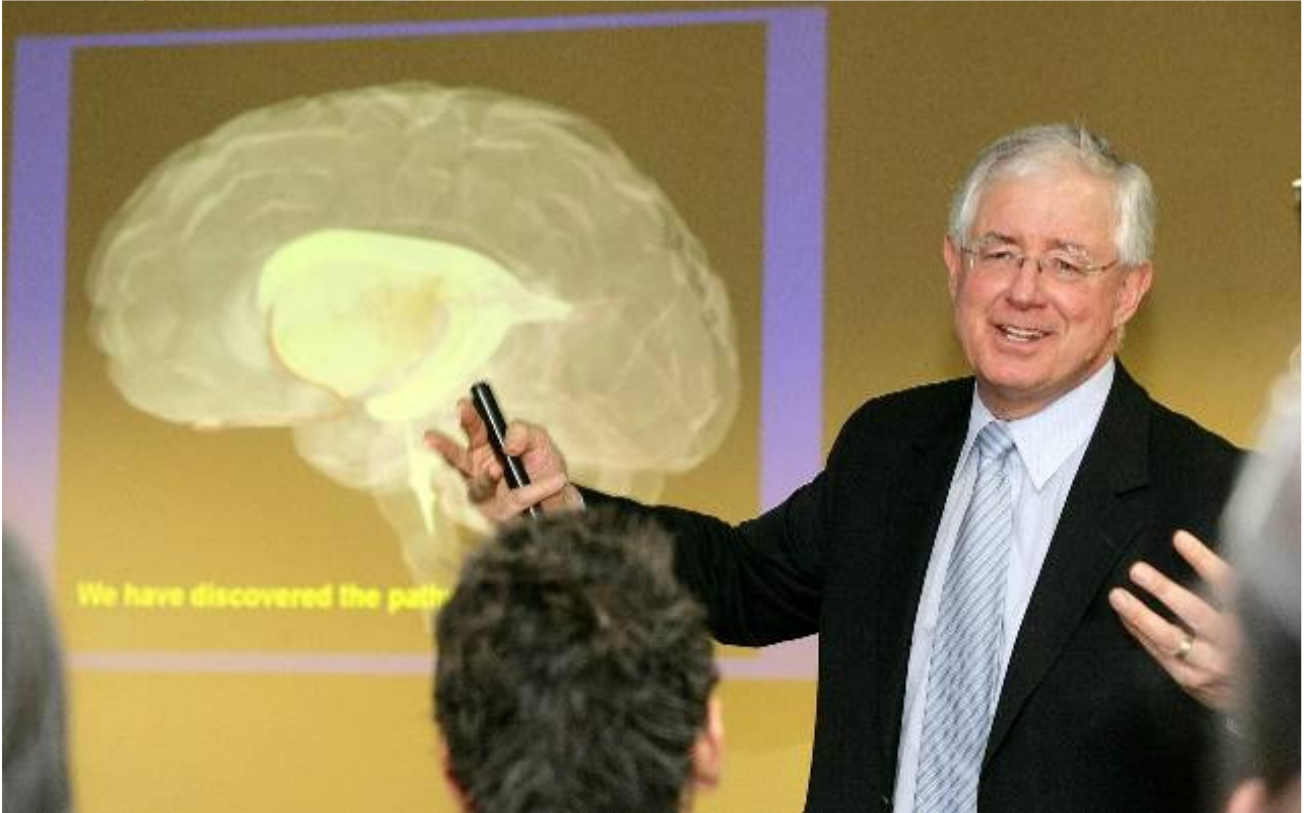


# Polio News

Post Polio Support Society NZ (Inc)

August 2009

## Coming to Conference: Professor Richard Faull



Professor Faull, in the Faculty of Medical and Health Sciences, has been a member of the University of Auckland for 29 years. He graduated in medicine from the University of Otago in 1970, before studying for a PhD in neuroscience at The University of Auckland, graduating in 1975.

Professor Faull is recognised internationally as a leading expert on the anatomy and chemistry of the mammalian brain and on neurodegenerative diseases of the human brain. His publication record

and research spans 35 years and encompasses all major regions of the brain and spinal cord, as well as the science of the diseased human brain in Huntington's, Alzheimer's, Parkinson's, epilepsy and schizophrenia.

His research provided the first evidence that the diseased human brain can repair itself by the generation of new brain cells, and in a 2007 landmark paper in *Science* showed for the very first time the pathway for new brain cells in the human brain.

### What's in this issue

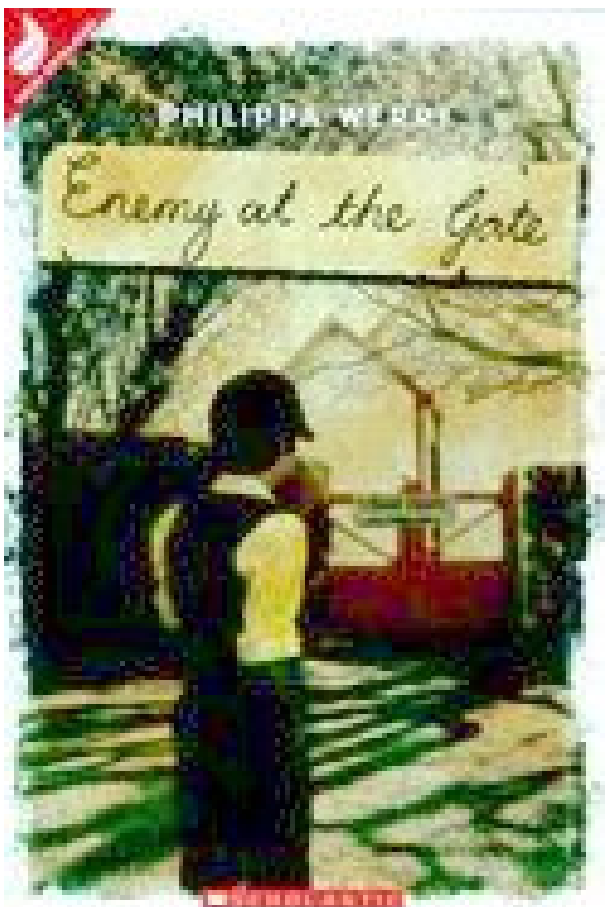
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## Coming to Conference Author Philippa Werry, 2009 Junior Fiction Finalist

One of our conference speakers will be author Philippa Werry. She wrote the book about polio called "Enemy at the Gate". Philippa will speak about her research into polio and its history.

**Don't miss this opportunity!**  
**Saturday morning, 12<sup>th</sup> September**  
**Brentwood Hotel, Kilbirnie, Wellington**

**Philippa will sign her books and have them available for sale**



### **Enemy at the Gate**

In 1936 a deadly disease has New Zealand terrified. Known as infantile paralysis, or polio, the disease appears to strike at random. Schools close. Going to the pictures is out of the question. Seeing your friends is dangerous. Caught up in the confusion and fear, 12-year-old Tom finds refuge in his dream: to run in the Olympics like the famous Jack Lovelock.



**Philippa Werry** was born in Christchurch and is a trained librarian. She was inspired to write *Enemy at the Gate* by a story often told by her father-in-law about his childhood. When he was about eight years old, he and his younger brother were sent to live on a farm in the Peel Forest in Canterbury. They spent three months camping in a tent in a field, seeing nobody except the relatives who owned the farm. This was because there was a polio epidemic, and their parents decided this was the best way to keep them safe. Philippa thought this was a really interesting topic, so she started to research more about it.

## From the President's Chair

Spring is almost here and there are early signs with daffodils, camellias, violets and daphne, bravely pushing through the cold ground ready to delight us as the weather warms. It has been rather a bleak Winter: weather-wise, money-wise and health-wise for many of us, and Spring will be more than welcome as it signals a new season.

We on the board of our society look forward to new challenges. In September at the AGM there is the re-election of officers, our conference speakers will bring up-dated reports on research into Post Polio Syndrome, and those attending have an opportunity to catch up with each other.

Prof Richard Faull is an engaging and informative presenter on his research of "Neurodegenerative Diseases". That sounds rather overwhelming but it does apply to us with post polio syndrome. There are other speakers and reports you will want to be informed about, especially an overall summation of the questionnaire so many of you filled in. I look forward to seeing you at conference.

I continue to dialogue with other organisations that might be useful links to us. I met with Heather Wilson, the President of ANZMES (ME/Chronic Fatigue Syndrome) attended a seminar by Dr Ros Valling who is also a member of our society and then met Prof Faull when he spoke in Hamilton. I will travel to Whangarei for their August AGM and PPSS meeting.

I would like to send my best wishes to those recovering from illness or surgery. My condolences to the families of our members who have passed away recently. If there is anything we as your

support society can do, please let us know.

Looking forward to Spring.

From my wheelie friendly chair

Edith



### New Website Now Functional

The Post Polio Support Society (NZ) has a new face to the world. Edith has drawn together a large number of ideas from Society members, and her husband Noel has spent hours at the keyboard putting it together.

You will find the fresh look at [www.postpolio.org.nz/home](http://www.postpolio.org.nz/home)

PPSS NZ (Inc)

# ANNUAL CONFERENCE 09

Friday September 11th  
Saturday September 12th



**Brentwood Hotel, Kilbirnie, Wellington**

## Guest Speaker: Professor Richard Faull

International Researcher on Neurodegenerative diseases  
Holder of the Rutherford Medal, NZ's top science award

Conference will begin at 12 noon on the Friday with Registration and a finger food lunch. This will be followed by a series of speakers. Professor Richard Faull will speak at 3 pm. His research of over 30 years has significantly advanced the understanding of Parkinson's, Alzheimer's, Motor Neurone Disease, and Epilepsy. **We are asking the question "What about Post Polio?"**

There will be a Conference Dinner on Friday evening after the Annual Meeting of our Society.

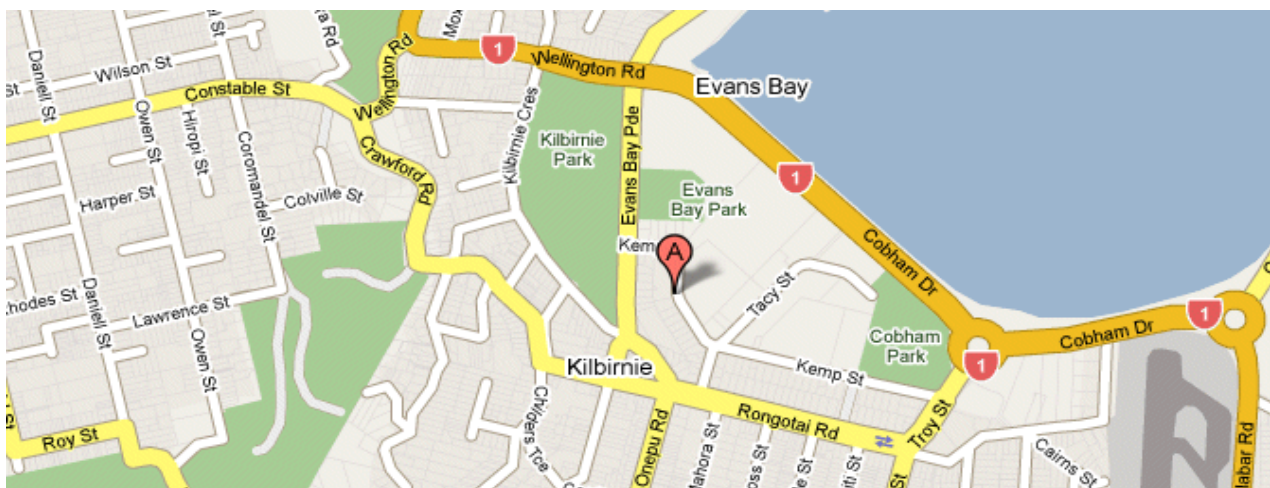
On Saturday from 9.30 we will have further speakers and discussions concluding at around 3 pm.

Philippa Werry, award winning author, will speak at 9:30am Saturday. Then she will be available for book signing.

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*Brentwood Hotel's location is shown by the balloon in the centre of the map*

## PPHI Conference - Living with Polio in the 21st Century



*In the May edition of PPSS NZ Newsletter Susan Kerr gave a full report of her participation in the Conference. Here are comments from other participants. (Source: Post Polio Health, Vol 25 no 3).*

### Conference Comments

Dr. Dale Strasser, Emory University School of Medicine, Center for Rehabilitation Medicine, Atlanta, Georgia, said, "Those with post-polio syndrome who are best able to cope are the ones who are able to articulate their needs, such as what is going on and what they need to be done." In other words, I think that the more we learn about post-polio problems and our own bodies, the better we will be able to handle life going forward.

-Ann Crocker, Maine

I don't think I ever felt so comfortable and unconditionally accepted by a group of strangers. The conference was a life-changing experience.

-Roxann O'Brien, Indiana

Writers Jacqueline Foertsch and Joyce Tepley, both from Texas, held a session on writing a "polio narrative." I was there to hear about how the tone and message of these narratives have changed and evolved over the past 50 years. I hadn't thought of writing a narrative myself, because acute polio hit me when I was 3 and I was hospitalized only three months,

so I have hardly any memory of the experience. Also, the after effects, compared to most of those I saw at the conference were mild and not dramatic. Many stories have been told already and I wondered what I could add.

I commented that my encounter with polio is more about the experience I'm having now with post-polio, not with the initial polio attack. Joyce answered, "That's your story" And she steered me to Kathryn Black's superb memoir, *In the Shadow of Polio* for an example of how exploring my family's memories can reconstruct not only my "lost" story of having polio, but their stories of how the family was affected, as well. I have saved the list of exemplary narratives and guide to writing one's life story hoping I will be inspired to start down that path.

-Tom Hanold, Pennsylvania



It was good to be with people who were going through the same thing that I am, and to not feel guilty if I got tired or was not feeling well.

-Mary Lynn Young, North Carolina

I had two insights. I knew that polio survivors were affected in different ways by the poliovirus, but the magnitude of the differences was very eye-opening. Even the effects of the post-polio syndrome is affecting us in different ways. I wish the world could see what I saw those few days of the conference — a great number of polio survivors — most of them strong, determined, unique and all very special, and each dealing with their lives in very different ways.

The second insight I had was in the session concerning the family. I had a chance to talk to a wife of a polio survivor, and she expressed that she was fearful. I have been the strong one in the family for all of these years but, with the decline in my strength and abilities, I hadn't thought about what they must feel. When I returned home, I asked them to think about what they would like to say to me on this subject, and we had family time in which they spoke and I listened. It was very enlightening.

-Sheila Kilgore, Florida



I observed that I didn't hear "Conserve to Preserve" once during the conference. Nor did any speaker allude to living with post-polio syndrome in reference to having finite use of remaining muscles or neurons. There was no mention of my atrophied leg having finite number of steps left which, once taken, are gone forever. No one advocated overworking my remaining muscles either.

Instead, I heard consensus that I need to pay much more attention to under-use and disuse of my viable muscles. Having post-polio syndrome does not excuse me from taking care of my health in general.

Dr. William DeMayo, John P Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania, gave the following illustration. He recommended that we be active to our limit.

Each polio survivor is distinct. I have distinct limits. I need to test and establish my limits by doing exercise and activities slightly beyond what I perceive to be my limit. To me, this is a significant modification to the "Conserve to Preserve" maxim. Using it, I don't really know my limits, because, according to it, the goal is to not use up remaining strength.

My experience is that I don't have difficulty in knowing when I overwork — my body rebels big time. But, do I know when I am under-using a viable muscle group? This is where I need the assistance of a trained physical therapist.

A clear message that I took away from the sessions is that we become much better at taking care of the challenges of post-polio syndrome if we take care of our health in general by weight control, maybe low-impact seated yoga, good sleep hygiene, relaxation techniques, improved assistive devices, and, of course, by having an uncompromising primary care physician.

-Baldwin Keenan, California

# Ban Ki-moon Applauds Rotary For Anti-Polio Campaign

New York, Jun 21 2009 10:10AM

## Press Release: United Nations

Secretary-General Ban Ki-moon called for a final push to eradicate polio worldwide, while paying tribute to Rotary International on Sunday for its tireless work in helping to stamp out the crippling disease.

Mr. Ban noted that when Rotary International launched its PolioPlus campaign in 1985, more than 125 countries suffered from polio endemic, and at least a thousand children were paralyzed every day.

Since then "millions of Rotarians have devoted endless volunteer hours in their quest to reach and vaccinate every child all over the world," he said in a keynote address to the organization's convention in Birmingham, United Kingdom.

The Secretary-General said that in the face of "funding shortfalls, cultural barriers, lack of political will, even risks to your personal security" Rotarians have raised over \$250 million to fund the fight against the spread of polio.

"You have met with everyone from village elders to presidents to get their support, met with religious leaders to gain their confidence, inspired business leaders to reach into their pockets and to speak up for this cause in the corridors of power," he said.

As a result more than two billion children have been immunized and over five million children who otherwise would have been paralyzed are walking, said Mr. Ban. "There are now only four countries that

are still polio endemic." Polio is widespread in Afghanistan, India, Nigeria and Pakistan.

"Now is the time to finish the job," said Mr. Ban, urging donor governments to help create a polio-free future.

At a time of global economic recession, the "choice is clear," he said. "We can cut back on health expenditures and incur massive losses in lives and capacity for growth. Or we can invest in health and spare both people and economies the high cost of inaction."

Mr. Ban dedicated the Polio Eradication Champion Award he received from Rotary International today to three polio workers who were killed last year in Afghanistan. "They were on their way to prepare for a vaccination drive when their convoy was ambushed by a suicide bomber," he said of Mamoon Taher Taheri, ShamsulHaq Kakar and Azizullah Almas.



*A Rotarian checks the finger of a child to see if they have been vaccinated against polio.*

## Polio workers killed in the line of duty

### Attack in southern Afghanistan a reminder of the dangers faced by public health workers

Two doctors on WHO duty and their driver were assassinated today by a vehicle-borne suicide bomber in Kandahar province of southern Afghanistan. Dr Shamsul Haq MH Kakar, Dr Mamoon Taher Taheri, along with their driver Azizullah Almas from the UN Assistance Mission in Afghanistan, were on their way to prepare logistics for a polio vaccination campaign in the region next week when their convoy was attacked. This tragic incident, along with an armed attack in Somalia this summer which seriously wounded two polio workers, are stark reminders of the risks faced by those working for public health in many parts of the world.

Throughout the 20 years of the Global Polio Eradication Initiative, vaccinators and other polio staff have faced the risk of murder, assault, kidnapping and natural disasters on all continents, despite UN security measures. The vast majority of these workers are volunteers; nearly all - staff and volunteers - live and work in remote or disadvantaged areas, to ensure that every child has access to vaccination.



*Afghanistan*

The United Nations Secretary-General has condemned this recent attack in the strongest possible terms. In tribute to the

victims, the polio vaccination campaigns which they were planning were not cancelled.

The Polio Eradication Heroes Fund recognizes health workers and volunteers who have incurred serious injury or lost their lives as a direct consequence of their participation in polio eradication activities. The families of the workers receive a certificate recognizing the victim's heroic commitment to polio eradication and a cash tribute. Those wishing to give may do so online or by contacting the Polio Eradication Heroes Fund at the CDC Foundation, 50 Hurt Plaza, Suite 765, Atlanta, GA 30303, USA.

In 2008, 1210 children worldwide (and 16 in Afghanistan) have been paralyzed by polio, which can be prevented by an oral vaccine and is the target of a global eradication effort led by national governments. Nearly half the Afghan children who contracted polio this year are from Kandahar province itself. In southern Afghanistan, uncertain and unstable security conditions have made it increasingly dangerous for medical workers and volunteers to move about vaccinating children during the large-scale immunization campaigns which underpin the effort to eradicate polio. While nationwide campaigns aim to cover over 7 million children under the age of 5 years with vaccine, polio remains mostly concentrated in this conflict-riven region, with a target population of around 1.2 million.

## Regional Events

### Northland

Warm winter wishes to you all from the not so winterless North! We have had our share of wet, wild wintry weather up here this year, but I'm sure that you South Islanders have suffered a lot more with the cold, icy conditions! We'll all hope for warmer weather soon!

Our last group "get together" was to Cobb and Co for a friendly, warming luncheon enjoyed by 16 of us! We were very pleased to welcome a few new members from further afield, including Melva from Hikurangi, and Peter and Shirley from Dargaville. We hope they will be able to join us more often!

We look forward to welcoming our President Edith to our next meeting on 12th of August. We hope to have as many members from around the North as possible to that special occasion! Phone Ruth on 09 4352168 or Dorothy on 4370271 for more information.

Till next time, take care!

Ruth Inglis.



*Edith, Ruth, and Betty*

### Christchurch

The Alps have never looked better. Complete with snow to foothills level they give the impression of being only a stroll away and make a glorious sight in the morning sun.

Yes, it has been a cold winter but that has not kept Christchurch members from getting out and about as was demonstrated when 44 people turned out on a midwinter's night to celebrate the 20th anniversary of our group.

The meal was great and we were thrilled to have four of our founding members attending. Tales of the early years were recounted and Pam Owers, who played a leading role in the formation, was presented with a bouquet of flowers.

A month earlier, in May, a full coach load of members and friends joined in a jolly ride through North Canterbury farmland on a mystery bus trip. The mystery was resolved when we stopped for lunch at a little – known Country Lodge a few kilometres from Rangiora and later completed the journey through Oxford and back to Christchurch.

George Ross



*Clockwise from front left:  
Joan Radburn, Kath Berryman,  
Pam Owers, Noeline Weakley*

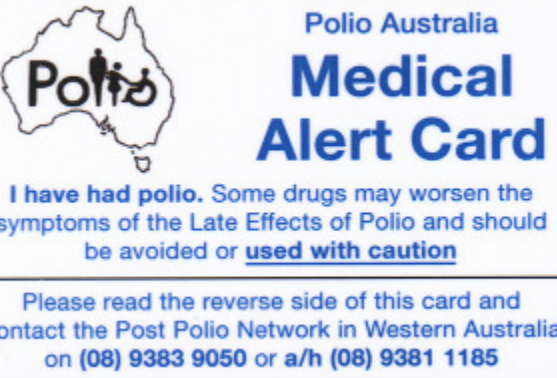
# Australia

## Medical Alert Card

Polio Australia produces a Medical Alert Card. It is designed to alert health carers in an emergency of precautions for polios.

*The front of the card.*

*The reverse of the card.*

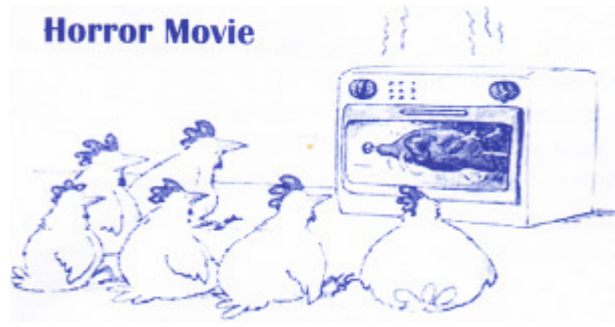
	<p>Polio Australia issues the following International Medical Alert for polio survivors.</p> <p><b>NOTE:</b> These drugs may worsen post polio symptoms and should be avoided or if absolutely necessary - <u>should be used with caution</u></p> <ul style="list-style-type: none"> <li>● cholesterol reducing drugs eg statins, lipitor, zocor etc</li> <li>● beta-blockers eg betaloc, inderal, tenormin, atenolol</li> <li>● benzodiazapines eg valium, serapax, ativan</li> <li>● CNS depressants eg mogadon, normison, tramal</li> <li>● muscle relaxants eg scoline atropine, buscopan</li> <li>● local anaesthetic incl eye drops eg ligno - &amp; xylocaine</li> <li>● general anaesthetics - all types - monitor patient with greater care. Avoid pre-med &amp; muscle relaxants.</li> </ul>
<p>This card is the same size as an eftpos card, or a driver's licence.</p>	<p>Dr Liz Falkner answers a question about Beta Blockers later in this edition.</p>

## Prosthetics and Orthotics

A prosthesis (plural prostheses) is any device that **replaces** a part of the human body. The field of making prostheses is collectively called Prosthetics.

An orthosis (plural orthoses) is a device to make part of the **body straight** (reduce deformity) or to **support and control** a weak or diseased part (prevent deformity). Some examples are leg braces, back braces, and neck collars. The field of making orthoses is collectively called Orthotics.

A professional who prescribes, manufactures and fits prostheses and orthoses is a Prosthetist - Orthotist.



**PPS**  
 Post-polio syndrome (PPS, or post-poliomyelitis syndrome) is a condition that affects approximately 25–50% of people who have previously contracted poliomyelitis - a viral infection of the nervous system - after recovery from the initial paralytic attack. Typically the symptoms appear 15-30 years after the original infection, at an age of 35 to 60. Symptoms include acute or increased muscular weakness, pain in the muscles, and fatigue.

## Editorial

### On Reflection

I'm a teacher at St John's College. As part of the College's Special Character (as a Christian institution) colleagues share something significant. It's called Tuesday Reflection. My turn was mid August.

I succumbed to the flu early August, and apart from the usual muscles aches, my polio leg ached more than the rest of me combined. This led to my Reflection. I talked, and showed pictures, about polio and its effects and shared how it had affected me. It was a bold move, because I am a private person and have never publicly spoken on the subject. I made the point that immunisation is essential, and that NZ is well behind in its inoculation rate!



Dr Nikki Turner says nearly 70,000 children under the age of 5 are at risk of catching measles.

The responses from my colleagues fell into two categories.

1. Younger colleagues really didn't know about polio or the damage it inflicted.
2. Many older colleagues had a personal story of a family member who contracted polio, or of a school closure they endured, or of the awful feeling of uncertainty in the face of an epidemic.

The second set of responses pleasantly surprised me. Polio is not a forgotten event, and there is still a significant awareness of its effects. Yes indeed, we are still here, and more positively, we are still remembered. ☺

Cheers, David

## Waterproof KAFO

by Darren Pereira

*From Polio Perspectives Vol 21 No2  
Winter 2009*

A waterproof Knee Ankle Foot Orthosis (KAFO) has been in development over the last 12 months. Many clients, who wear a KAFO for walking, prefer to stand in the shower instead of using a shower chair. This functional activity often exposed the client to a very significant falls risk and further reliance on the good leg for full standing support.

Five polio clients now wear a waterproof KAFO. The design is a total contact laminate with full lining if required. It can be any colour, designed to be strapless if required and has its own build-up/waterproof tread. Although primarily for showering, clients are now utilising the KAFO for swimming, around the pool, surf fishing and general beach outings.



## About Us

The Post Polio Support Society of 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 physically or by telephone conference, and the annual general meeting of members is held in September.

The Society's newsletter, ***Polio News***, is published four times a year (March, May, August, November) and is sent to all members.

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

**Disclaimer:** Opinions expressed in the newsletter are those of the writers and not necessarily those of the Society.

**Acknowledgement:** This newsletter has been paid for by a grant from the Lottery Grants Board and the JR McKenzie Trust, to whom the Society expresses its thanks.



## YouTube

YouTube is a video sharing website on which users can upload and share videos. It is now operated as a subsidiary of Google.

Most of the content on YouTube has been uploaded by individuals, although media corporations including CBS, the BBC, UMG and other organizations offer some of their material via the site, as part of the YouTube partnership program.

Unregistered users can watch the videos, while registered users are permitted to upload an unlimited number of videos.

YouTube can be found at <http://www.youtube.com/>

If you search for **polio** on YouTube videos of recent polios appear, as well as brief history clips. Here is a screen shot of leg callipers. The video shows them in use.



YouTube has become an educational tool. All manner of content is posted there, and it is a great resource if you wish to show others about polio.

## Betablockers

I wonder if you could find the answer to this question? I did ask at a seminar we went to but didn't hear the answer very clearly. The answer used medical and medication terms that were unknown to me. In your travels you may have come across this...

### Question

Betablockers are said to be not good for polios so what is to be used in place of them? Can we just stop taking them? During the past week or so I've had higher BP and have had to use the spray. I had just started to use the Betaloc 47.50 (ex Dr) again after using the 23.75. Now I'm to start the 23.75 again. (If you've never had to use heart meds this will all seem gobbledegook.)

### Dr Liz Falkner answers



Beta-blockers are drugs that stop (ie BLOCK) some of the ways our bodies respond to adrenaline. We all know adrenaline readies us for 'fight-or-flight' - or fright!

1. Adrenaline speeds up heart-rate - beta-blockers slow the pulse.
2. Adrenaline opens up the bronchioles (fine breathing-tubes) - beta-blockers

can narrow them, causing asthma (which is really the worst of the possible side-effects of the beta-blockers.)

3. Adrenaline increases circulation to muscles, beta-blockers reduces circulation, causing cold hands and feet - which polios emphatically don't need!  
(Beta-blockers can also cause erection problems and depression)

Beta-blockers are used for three real reasons:

1. Reduce blood pressure.  
Dose range (for metoprolol = Betaloc or Lopresor) is 23.5 mg to 200 mg daily.
2. Slow heart rate (Hugely useful for people who have attacks of rapid palpitation - no real alternative, as other drugs are far more likely to have side-effects).  
Combination of the above means beta-blockers are especially useful for people whose BP shoots up when they are stressed.
3. Reduce the likelihood of a second heart attack, or even a first one in folk with many risk factors. (Only a small dose needed.)

There are many different beta-blockers. Each has a different spectrum of effects - some being more useful for reducing pulse rate, some for BP.

Metoprolol comes roughly in the middle. As regards metoprolol and polio, I perceive the main practical problem being with our circulation - quite likely with the small dose we will notice no problem.

The question asks about doses of 23.5 - 47.5 mg of metoprolol. Probably the person asking will be fine with this sort of dose, but if they start developing even worse circulation problems - like getting chilblains for first time since childhood - it might need re-consideration.

## Bill Gates says...

### New Delhi

24 July 2009

India's inability to stamp out polio has raised serious fears that the virus causing the crippling disease might never be eradicated.

In an ominous warning, Microsoft founder Bill Gates told *Times Of India* on Thursday that those implementing the programme, funding agencies and common people will soon feel fatigue, thanks to the virus constantly making a comeback.

Gates said, "We have spent lots of money in India's polio programme. We have to get polio eradicated with tremendous urgency. If we don't get it eradicated now, we may never be able to get it done."

Polio cases have been piling up in India every year. Even though transmission of P1 (the most dangerous strain of polio virus) has almost been arrested in Uttar Pradesh and Bihar in the last one year, India is sometimes even earning the dubious distinction of having the world's highest number of polio cases.

Gates said, "Since we are close to eradicating polio, with the number of cases actually low, the amount of money being spent on one child death is astronomical."

India is just one of the four countries grappling to control the disease that affects children below the age of five. "In parts of UP and Bihar, even 10 doses of the oral polio vaccine haven't been able to protect children against polio. A combination of Injectable Polio Virus (IPV) and OPV may solve the problem. India at some point may want to use IPV in the routine immunisation programme. I agree that adding an injection is not a trivial thing," Gates said.

Criticising India's low immunisation rates, Gates said countries like Africa and Bangladesh were better off than India on this count. "Take measles for example. It's hard to find a thing that Africa does better than any other place. However, in controlling measles deaths, Africa has done better than India. In India, the whole issue of immunisation is pretty chaotic right now. You'll face both a demand and a supply problem. You have to get mothers to want their children to get the vaccine and on the other hand get competent people providing it," Gates said.

## Directory

Information about membership and local support groups

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**Website:** [www.postpolio.org.nz](http://www.postpolio.org.nz)

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