



Polio News

Post Polio Support Society NZ (Inc)

May 2009

Post-Polio Health International 10th International Conference



Pam and Susan - last night at conference



The dinner queue



Barb, Pam, and Susan - International Post Polio Support Organisation Bulletin Board members



Alumni of Warm Springs Polio Foundation



Karen from Colorado and Susan. The conference bag reads "We're still here"



The Little White House with access ramp at right

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Post-Polio Health International

10th International Conference 23rd to 25th April 2009

Living with Polio in the 21st Century

Last month, I felt very privileged to attend PHI's 10th International Conference in Warm Springs, Georgia, USA, representing all the members of our New Zealand Post Polio Support Society. It was our Board's aim that we should send one person to collect the latest ideas, experiences, innovations and results of research and technology that is available; pass on updated information helpful to our Health Professionals and to our members; find out about countries who are having positive outcomes for those coping with Polio into old age; forge world-wide links that will be ongoing, to share experiences and successes.

The conference took place at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). The campus was originally set up by Franklin Delano Roosevelt as a rehabilitation centre for polio survivors. In fact, many of the attendees at the conference were treated there themselves as children. These were the "alumni". For them, the return there was tinged with nostalgia, as well as the desire for knowledge.



FDR in action

The staff at RWSIR welcomed 436 registrants. In attendance were survivors, family members and health professionals from 11 countries (46 individuals) and 39 US states and the District of Columbia. It was an overwhelming experience to be surrounded by so many people, most of whom were polio survivors. Being on a scooter, walker, crutches or wheelchair was the norm and we knew that we were among friends. All those new friends and approximately 50 seminars were compressed into 3 short days. We were collected from our accommodation about 8 am each morning and returned about 9.30 pm. In each time slot, there were, on average, 5 seminars to choose from. I tried to choose what was useful to as many of us as possible and occasionally had to decide that some venues were too far to walk to, as the campus seemed enormous.

Nearly all the presenters had submitted summaries of their talks, and we came away with 3 booklets, one for each day, containing these summaries. There will be a CD available soon from PHI with the remaining notes. This meant that we felt easier in our minds about making the choices, as so much information was available from what we had to miss.

In the opening plenary on Thursday, after lunch, we met the representatives of RWSIR and PHI. The PPS Society of Japan gifted a PowerPoint presentation beforehand of music and photographs. That day I chose to attend Tools to Use in Evaluating Treatment choices presented by Barbara Duryea and John P Murtha. Many notes were provided. My next

choice was to have been Finding and Disseminating Information through Support Groups, but as I could not walk fast enough, the room was full! However, there were sheaves of written information and these are invaluable. Instead I went on to Frederick Maynard's Demonstration and Discussion of a Post Polio Examination (Part One). Dr Maynard visited New Zealand in the nineteen nineties so some of you may remember him.

A simple Subway type dinner was provided, but because of the numbers of people, the queue was a mile long and took an hour to process. The weather outside was hot and balmy. After that, the last session of my day: Polio Narratives: Readings and Discussion of the Writing Process. Then back by shuttle bus to my room, where I crashed into a jet-lagged sleep.

Friday I attended an interesting Research seminar, PHI Research Grant: Regulatory T cells as a Biomarker for PPS, presented by Rahnuma Wahid. I hope to be able to give much fuller details of topics in later articles for the newsletter. Suffice to say for the moment that it is very encouraging that new research is still being carried out on a supposedly almost extinct problem. Following this, ironically, was a long walk to Finding Causes of and Managing Fatigue, presented mainly by Frans Nollet from Amsterdam. I then squeezed in an extra session on Current Epidemics: Status, Lessons and Tasks. This was a very informative session on the Global Polio Eradication initiative, spearheaded by WHO, CDC, Rotary and UNICEF. At this point I would have like to have attended the second part of the Fatigue Demonstration, but it was too far away, and I opted for a very useful session on Effective Family Communication. This day ended with Pizza and a choice of films. I chose the film Warm Springs, an HBO production about FDR and his life with polio and the setting up of the Warm

Springs campus. There was popcorn and soda: handkerchiefs would have been a welcome addition.

It was Saturday, the last day. I opted for First Step in Pain Treatment: Finding the Cause. There was a panel of 4 presenters and I found the session a bit slow, but some really good notes were provided by Dr Amy Clunn. I followed this with an invigorating seminar entitled Learning from Wise Elders. This certainly needs a whole article to itself and relates to a 2 part study carried out in 2006, and presented by Sunny Roller and others. The study involved finding people in US PPS Societies who had dealt successfully with their lives in the face of disability and what they could offer as words of wisdom.

I then took a little time out to visit the museum and FDR's Little White House on the campus.



"I am deriving wonderful benefit from my stay here." Mr Roosevelt said, "This place is great. See that right leg? It is the first time I have been able to move it at all in three years"

The closing Plenary was presented by David M Oshinsky, winner of the 2006 Pulitzer Prize in History for his book: Polio: an American Story (The Crusade that mobilized the Nation against the 20th Century's most feared disease. He was an entertaining speaker and signed copies of his book for those that had them.

Dinner was a Southern "boil up" over by the lake at "Camp Dream. I could not believe that it was all over. The next morning I was away and off to my flight from Atlanta.

I did manage to find some time to make new friends. We also had a special meeting for those who were international delegates (including New Zealand, Australia (5 delegates) Nigeria, India, Canada, Brazil, Denmark, Germany, Japan). Delegates were asked to say what it was their countries most needed in terms of PPS care. Needless to say, conditions in Nigeria seemed to be the worst, with few rehabilitation clinics or aids. Germany had conditions that seemed to be ideal and nobody seemed to need anything to improve their lives.



This is just my first brief summary. I will be doing a presentation at our Conference in Wellington in September. I warmly thank our Post Polio Support Society of New Zealand with assistance from the Duncan Trust for enabling me to attend on behalf of us all.

Susan Kerr

My Days with Polio By Virginia A Miller

I was so little but I still recall
The day I got up and took my first fall,
Tried to stand but could only crawl,
Over to mommy, I started to bawl.

"Why can't I walk anymore," I said,
As they picked me up and put me back on the bed.
Scared looks was all I could see.
"I wonder what it is that's wrong with me?"

Next thing I knew, to the doctor I went,
When I woke up, I thought I was in a tent!
But no, it was not ten I was in.
It was a crib! I was a baby again!

No, no! Let me out of here!
I'm sorry but you can't yet my dear.
For you see, it's a bad thing that has happened to
you.
You may never walk again, and this is so new.

We know nothing about this horrible disease,
And your legs will have to be handled with ease.
Exercise, exercise, is all we can do,
We really don't know hat this will do to you.

Polio will give you terrible pain.
It's the muscles we have to try and maintain.
So, it is there that I stayed for a year of my life
Learning to walk was a struggle and strife.

But walk, I did, with the help of supports,
I didn't care if I never played sports.
The crutches were set aside in the third grade,
The corset was small, so another was made.

No jumping, no squatting, no playing softball,
But I had no trouble laughing at all!
No high heels, no running either, for me,
But I could dance and was happy as I could be.

Now here I am, at the age of fifty,
And life, at this time, isn't too nifty.
I'm back on crutches and it's hard walking.
But thank God, I'm still writing and talking!

From
http://www.ginnyanmiller.com/My_Polio_Poem.php

From the President's Chair

You are holding in your hand another excellent **newsletter** which David has put together. This newsletter is our link to you the members of our Society. It is our voice letting you know what is going on in the society, and what we are doing on your behalf. Enjoy reading it and pass it on.

The response from the very comprehensive **questionnaire** has been absolutely awesome. More than half have been returned so far. We will have a breakdown of the data ready for our September Conference. The results help give us a clearer picture of the situation facing both you and our Society today.

As a board we have been quite busy working on a **strategic** business plan with board members picking up a portfolio which interests them. There is still much work to be done on this, but we are endeavouring to have an outline in time for our Conference in September.

- In March, Edith, Des (vice-president) and Ethne Crabb, and Anne Mace (board member), attended the 20th anniversary celebration of the Auckland Post Polio Support Group.
- In April Edith spoke at the Fairfield Rotary and later helped with their "End Polio Now" booth at the Regional Rotary Conference in Tauranga.
- In May, Anne Mace and Edith attended a workshop on "Ageing and Disability" at CCS Disability Action in Auckland.
- Philippa McDonald, a former board member, attended an "Equity for

Illness" meeting in Wellington, on behalf of our Society.

- The Tauranga, Whakatane, and Eastern Bay of Plenty groups held a combined meeting in Whakatane. Edith and husband Noel enjoyed a happy lunch with the 18 members.
- Susan Kerr (board member) attended the 10th International Conference in America "Living with Polio in the 21st Century" on our behalf and for our benefit.

In closing, will you consider attending our National Conference in September? Details are on the next page.

Keep healthy during the winter.

From my wheelie friendly chair

Edith



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 over 30 years has significantly advanced the understanding of Parkinson's, Alzheimers, Motor Neurone Disease, and Epilepsy.

We are asking the question "What about Post Polio?" Dr Faull will also join us at the Conference Dinner on Friday evening after the Annual Meeting of our Society.

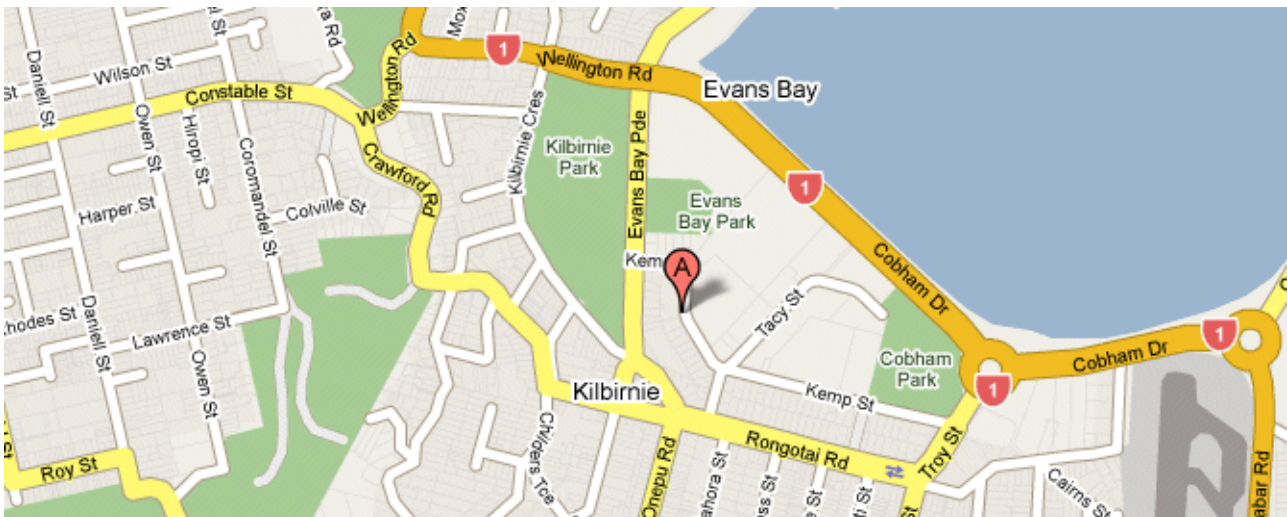
On Saturday from 9.30 we will have further speakers and discussions concluding at around 3 pm. More

programme details will follow in the mail with the Membership subscription invoice, in late June.

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

Necessity, Mother of Invention, and all that ...



Bathboard, perched on rubber-cuffed crutches.

Just a piece of old wood, . . .

Say what you like about the latest disability aids but let me tell you about my third-favourite piece of getting-it-done equipment. It's a piece of leftover totara book shelving 270mm wide, 20mm thick and as long as the width of a bath -- so there's the giveaway.

My most useful and therefore favourite items of mobility gear are my in-the-house Shoprider mobility scooter and my crutches, now that I've fitted them with some neoprene which has totally stopped the hard plastic cuffs from digging into my ageing forearm skin.

Both have been a bit of a challenge.

The ageing scooters electrics are a bit iffy and need regular attention. From me, that is. Living near the sea means the contacts need cleaning regularly. Sometimes at night -- which is when I rely on wheels since I don't wear my AK calliper to bed -- I have to wiggle a battery wire so I can ride to and from the bathroom.

And the crutches . . . well, I thought there'd be something off the shelf to soften the impact of their skin-damaging hard-plastic cuffs; optimism sometimes is a let-down. A visit to orthotics was unproductive so I asked for a piece of neoprene. A technician assessed the problem, didn't think it would be possible to fasten it over the cuffs. But I persevered and explained how I would glue and sew it in place and eventually a table-mat-sized piece was produced - along with a request for \$24 - plus the same for another piece for the other crutch.

Um, no. Not today I thought, knowing I could buy a wetsuit on TradeMe for the same money and have enough neoprene for two more sets of crutches. What we'll do, I said by way of helpful alternative, is book me into your next orthopods clinic and Ill talk to him about these bruises on my forearms.

They relented, decided to give me the bits of neoprene and add the cost to whatever

prescription stuff I might have on file from times past.

Worked a treat, the cuff-cushioning. I cut the neoprene carefully, tacked the raw edges together bit by bit with brush-on superglue, then blanket-stitched the joined edges with needle and thread.

Back to the totara plank: My piece fits snugly across my bath, between the moulded upturns on each side. It slides back and forth within the edges of the tub. Other bath designs might need some careful wood-cutting, or even cleats under the plank, to be as secure.

The reason it's number three on my list is that it enables me to use the bath. I slip off the seat of my scooter which is so manoeuvrable and able to park right against the side of the bath in our very small bathroom, then onto the plank while the bath is filling, and then I can lower the ageing body into the water.

Great that I have enough upper body strength to both lower into and elevate back out of the water - the alternative would be a mechanical device that I can't imagine being made available without much grovelling to OTs and Enable.

Great that totara is so strong and light enough to lift from behind me, once I'm in the bath, and park along near the taps so I can lie down in the bath. Great that totara doesn't need painting - its natural smooth grain is non-slip and quickly dries in a few hours.

And great that this virtually value-less piece of timber can deliver me safely to the relaxing, recuperative, soul-warming effects of the simple bathtub.

Jim Webber

Martha Mason

6th May 2009

An extraordinary North Carolina woman named Martha Mason died on early Monday in Lattimore. Mason was 71 years old and had spent 61 years of her life in an iron lung. She had authored a book on her eventful life. A documentary on Mason's life was produced by Mary Dalton in 2006. Dalton, who was deeply interested in Mason's life, is an associate professor of communications at Wake Forest University. Though paralyzed by polio neck downwards in the year 1948, Mason not only continued her studies in the University of Wake Forest, but actually graduated at the top of her class 1960.

It was only with the technological development of a voice-recognition computer that she could start writing her book in 1994. Mason's book is titled, "Breath: Life in the Rhythm of an Iron Lung," and it was published in 2003. The 1948 epidemic afflicted her with polio, and in her iron lung, Martha survived longer than any polio survivor in a lung. she was told that she would not survive more than a year.

In September 2003, Wake Forest University honoured Martha with the Pro Humanitate Award. In 2004 the Gardner-Webb University awarded her an Honorary Doctorate in Humane Letters. Martha "lived above" her disease, and as she had always said, she did not let polio get the better of her till the last breath of her life. Her life is truly one of courage and inspiration.



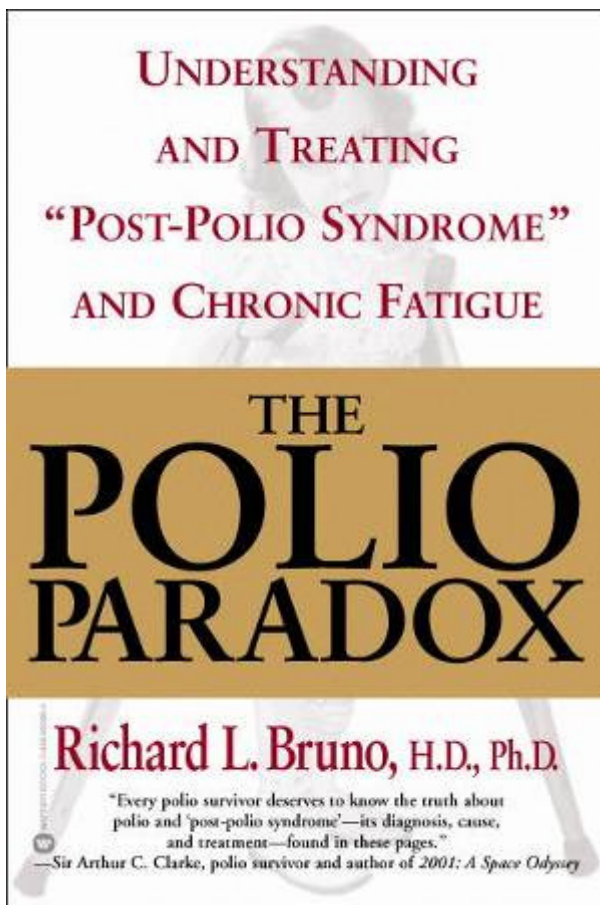
Martha and Mary

The Polio Paradox

Understanding and Treating “Post-Polio Syndrome” And Chronic Fatigue

By Richard L. Bruno, H.D., Ph.D.
First Published 2003

Synopsis of a review by Arthur L. Dobson with permission from Dr Bruno. The full review is in the TAS Polio News, March 09



In this book Dr Bruno describes the situation of a number of polio survivors and how their lives were improved by various strategies they employed after their consultations. He then provides a

thought provoking statement that applies to many polio survivors and those people with whom they share their lives.

All polio survivors are caught in paradoxes: -

Paradox 1

Polio was thought to be a “stable disease.” Once polio survivors recovered muscle strength after the polio attack, their physical abilities were supposed to remain for the rest of their lives. However, contrary to this common belief, polio survivors’ strength and abilities were ebbing away.

Paradox 2

In the 1980s, doctors were ignoring and rejecting the same polio survivors whose plight had riveted the attention of the world’s medical community and spurred it into action just thirty years before.

There is no question that polio survivors new symptoms are real - and that there’s no more time to waste in treating them. Half of North America’s estimated 1.8 million polio survivors are in their forties, fifties, and sixties, at the peak of their careers, the apogee of their lives, and they are watching as new symptoms cause their ability to work and function ebb away. This need not happen! After two decades of research, we know why polio survivors are having new problems, and we know how to treat and manage them. It is time to set forth the facts - to set the record straight - once and for all.

Regional Events

Northland

Hullo again from us all in the North. Yes, we are still going strong despite dwindling numbers attending our meetings, due to ill health and travel distances. However we are in good heart and enjoy our bi-monthly luncheon outings.

At our recent meeting we had a most interesting speaker from the local Age Concern branch. From her talk we learnt the benefits to be had from becoming a member of Age Concern.

Our June meeting will be another enjoyable lunch together at Cobb and Co. on 10th June, and then at our August meeting we are looking forward to welcoming our new President, Edith, if she can fit a visit to Whangarei into her busy schedule this year!

Keep warm and well through the winter ahead. We hope it won't be too long or harsh!

Ruth Inglis.



A modern Iron Lung – a bit different from the device in the picture on page 8.

Nelson – Top of the South

Hi everybody,

Hope this finds all well with you and yours, and that you are enjoying glorious autumn weather as we are here. A get-well-wish goes out to those of you who are unwell and a particular recovery wish to Pauline Hennessey after her recent bad fall. No more dancing with the stars Pauline!

I recently visited an excellent shop called "Access / Mobility" which opened in McGlashen avenue, Richmond just before Christmas last. Well worth a visit. All things are catered for both large and small, from wheelchairs and raise up beds to small gadgets for hand use and bathroom and toilet aids. If they haven't got it they will access it for you, nothing is a trouble. These people are worth supporting and encouraging in these times.

Mid-winter luncheon

Saturday, 20th June
Anchor Bar and Grill
Vickerman St
The Port.
12.30pm

There is plenty of parking both sides of the road and good gentle ramp access to the building itself now, not as it used to be. Please let Rex or me know of your attendance by Tuesday evening, 16th June.

Rex 5477043
Jenny 5451030

I wish everyone a cheery and healthful winter.

Rex Wastney and Jenny Kissane.

Christchurch

Our group is nearing its 20th anniversary and to mark the event we are planning a special dinner at a local venue. Many of the original members still attend regularly and our numbers remain surprisingly steady thanks to occasional new members who compensate for the number of older members that we have lost.

We continue to hold regular monthly meetings to share experiences and listen to informative speakers and, almost monthly, go exploring some local (or not so local) attraction. Recent excursions have included an alpaca farm (see photo) and the Botanic Gardens. During May we will be setting off on a mystery coach trip with a fully booked bus.

I wonder how many folk completed and returned the survey form with the last newsletter? I struggled through it and must say I wondered about the relevance of some of the questions. I hope the results are of use to someone.

George Ross



One of our members up close to a friendly alpaca during our farm visit.

Western Bay of Plenty

Hi everyone.

Winter is definitely letting us know it has arrived over the last few days. Who would have believed people would be snowboarding on the sand dunes of Papamoa and Mount Maunganui but our massive hailstorm this week provided that opportunity!!

The weather was generally kind to us on May 6th however when we met with members from Whakatane, Opotiki and Kawerau at Skippers Restaurant in Whakatane, a great venue looking out over the Whakatane River and home to the Whakatane Sports Fishing Club. About 18 members of our joint groups enjoyed a happy get together with wonderful food and beverage together with plenty of talk!

It was great to have with us Edith Morris, our National President, and her husband Noel who had travelled through from Hamilton for the occasion. We appreciate how keen Edith is to meet with as many members as possible as well as making contact with post polio folks who may not be aware of our Society. Our thanks to the Whakatane group for organising this lovely outing for us all.

Our group looks forward to meeting with Waikato members for lunch in Matamata on May 23rd

Keep warm through winter.

Barbara Snaith

Waikato

A letter has been sent by Laura Landkin to those on the Waikato mailing list. It enquires if the recipients would like help or support relating to the effects of Polio. It also explains the purpose of the local gatherings – to offer a forum for sharing problems and issues specific to polio disability.

A combined meeting is planned for people from Waikato, Bay of Plenty, Rotorua, Thames Valley, etc. All folk are invited to lunch at Matamata on May 23rd.

The meeting will be at Raynor Lounge, Union Parish Church, 31 Peria Road, Matamata where there is plenty of off street parking.

Colin and Gabrielle Kemplen will give a fun talk about their tandem bike trips.

Lunch will be soup, buns, fruit, tea, coffee, and will cost \$6 per person. Please contact Edith if you intend to come.

Polio's Story



Visit <http://www.scq.ubc.ca/polio-a-virus-struggle/> for an interesting Graphic Novella history of polio. This is just one frame.



A combined gathering over lunch at Whakatane

Editorial

The Perks of the Job

A really great aspect of being editor is reading the interesting material that comes through my in-box. It ranges through many hues: serious, funny, absurd, tragic, inspiring, and so on. This month I have read a lot of Dr Richard Bruno's material, and learnt some interesting aspects of the behaviour of some Post Polio folk. In essence "you can lead a horse to water ...". Dr Bruno states that it is the polio survivor alone who will determine the effectiveness of any programme designed to manage PP symptoms. Those who want to help (family, neighbours, friends), and can see the need, won't achieve anything worthwhile if the "horse" is unwilling to drink. Polio survivors, fiercely independent and desperately trying to live normal lives, are not necessarily the wisest when facing Post Polio syndrome. Food for thought!

Thanks

Many thanks for all the good wishes and expressions of concern from you good folk when I reported my broken clavicle and ribs last edition. I am 90% recovered. The irony of insisting on clear floors at home so I didn't stumble and fall, then falling off my bike, has not been lost on me.

😊 ← wry grin!

Keep warm and well.

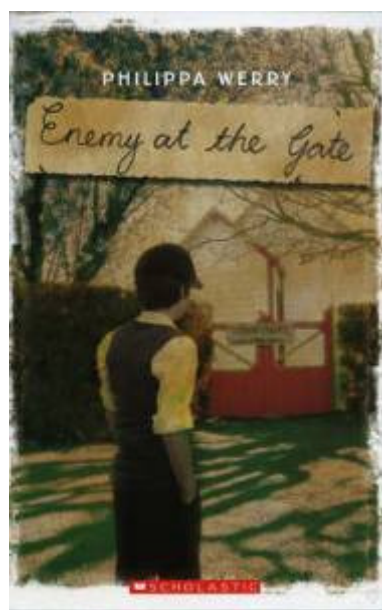
David

Book Review

Enemy at the Gate by Philippa Werry

Published in 2008. Target age 10 to 14 years but will appeal to all age groups. 2009 Junior Fiction Finalist in the New Zealand Post Book Awards.

The terrifying polio epidemic of 1936 is part of New Zealand's history, but this story re-visits this event through the eyes of a young boy. He and his family and school friends face increasing dread as polio's shadow comes closer and closer to their community in Wellington. Who in the neighbourhood will get polio? How will they all cope?



The story moves along at a steady pace, building curiosity right up to the last page. Philippa Werry has included historical events, and typical lifestyle and language to portray a truly New Zealand setting.

For most people polio is a forgotten disease, and this story subtly shows a new generation what it was like to live through that extraordinary time. I can wholeheartedly recommend this book.

Edith Morris
National President PPSS NZ

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.



Vivid Mobility Parking Spaces Deter Misuse

Research from CCS Disability Action shows that painting mobility parking spaces with vivid colours deters misuse.

Six mobility parking spaces were monitored during a study supported by Land Transport New Zealand, Waitakere City Council, Auckland City Council and Fulton Hogan. The spaces were monitored by Research NZ prior to being painted and twice again afterwards.

Before being painted, 55% of people using the mobility parking spaces were doing so illegally, without a valid mobility parking permit.

The parking spaces were then painted blue with yellow road markings by research partner Fulton Hogan. Three months later the rate of misuse had dropped to 51%. The parking spaces were monitored again three months later and the level of misuse had dropped to 42%.

During the same period the number of vehicles using the parking spaces with a valid mobility parking permit had risen from 40% to 52%.

Peter Wilson, Mobility Parking Permit Scheme Manager, finds the research encouraging.

“This study shows that increased visibility affects the rate of misuse and genuine mobility parking users benefit from the freed up spaces,” says Peter Wilson.

Recent amendments to Land Transport Rules mean people using mobility parking spaces without displaying a valid CCS Disability Action mobility parking permit will face consistent national penalties with fine increases expected to be set at \$150 by the Ministry of Transport.

“Mobility parking permit holders rely on these parking spaces to access and contribute to their community. Hopefully increased fines and more visible parking will mean more permit holders being able to access parking spaces in their communities”.

While the legislative change has a huge impact on access to public mobility parking there are still concerns with privately owned car parks and their mobility parking.

“It would be great to see private parking owners making their mobility parking spaces more visible and adopting some of the principles in the new legislation. Blocking disabled people from getting on with their business, shopping and leisure activities, is still a big problem in New Zealand.”

Government sends out strong message on misuse of mobility parking

The government has sent out a strong signal that misuse of public mobility parking spaces will no longer be tolerated.

Previously, mobility parking infringements and penalties were dealt with under local authority bylaws but amendments to Land Transport Rules, that came into effect on 17 January, means people using mobility parking spaces without displaying a valid CCS Disability Action mobility parking permit will face consistent national penalties.

Research undertaken by CCS Disability Action found that 50% of vehicles using a public mobility parking space were doing so illegally.

Parking penalties in New Zealand (\$40) are not much of a deterrent when compared to fines in England & Scotland

(\$2926), New South Wales (\$454 to \$545) and Chicago (\$784).



How to annoy others with your parking skills!

Stress Management

A lecturer, when explaining stress management to an audience, raised a glass of water and asked; “How heavy is this glass of water?”

Answers called out ranged from 20g to 500g.

The lecturer replied;

The absolute weight doesn't matter. It depends on how long you try to hold it. If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case, it's the same weight, but the longer I hold it, the heavier it becomes.”

And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on. As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden.

Whatever burdens you're carrying now, let them down for a moment if you can. So put down anything that may be a burden to you right now. Don't pick it up again until after you've rested a while.

Question

I read about cold intolerance, that Polio Survivors are always cold. My feet are always cold in the winter, but I have the most trouble in summer. I get exhausted in the heat, especially when it's humid. Is heat intolerance also a post-polio problem?

Dr Bruno's Answer

You bet. In our 1985 National Post-Polio Survey cold caused muscle weakness in 62% of polio survivors, muscle pain in 60% and fatigue in 39%. But that survey also found that 39% of Polio Survivors have fatigue when it's hot.

Whether it is cold or hot, polio survivors have three strikes against them when it comes to controlling their body temperatures.

First, the poliovirus damaged the hypothalamus, the part of the brain that serves as the body's thermostat.

Second, the polio virus killed neurons in the

spinal cord that make the veins in your skin become smaller or larger as the temperature changes. Basically, polio survivors' veins are always too big. When it's cold outside warm blood pools in those big veins near the surface of the skin, causing heat in the blood to radiate into the air, the skin to get very cold, and to look purple or even blue. When it's hot outside, or when polio survivors take a long hot bath or shower, the skin becomes lobster red as the veins and the arteries open wide and hot blood rushes to the skin. When polio survivors stand up, gravity pulls blood into the open veins in their legs and blood pressure can drop, causing fatigue, light headedness or even a faint.

And then there's the third strike: Polio survivors who have smaller leg muscles due to polio damage causing muscle atrophy, have more blood pooling in the lower legs. Since muscle contraction is needed to help to pump blood back toward the heart. So, since your body now can't regulate its own temperature, you will have to do it.

Directory

Information about membership and local support groups

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