



Polio News

Post Polio Support Society NZ (Inc)

May 2011

“LIVING WELL WITH POLIO”



Conference 2011 New Plymouth

12th to 14th August

The programme for the 2011 Conference is on page 2 and is repeated on page 16.

The Registration Form is on page 15. Please tear the Registration Form off, complete it, and return to Marie Frewin by July 31st

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Conference 2011

POST POLIO SUPPORT SOCIETY
NZ Incorporated

ANNUAL MEETING & NATIONAL CONFERENCE
The Quality Hotel Plymouth International

Friday 12th August to Sunday August 14th 2011

“Living well with Polio”



PROGRAMME

Friday 12th

- 15.30 Board meeting – Observers welcome
17.00 Registration Desk
17.15 **Official Opening** – His Worship the Mayor – Hon Harry Duynhoven
Special welcome to Rotarian Guests
END POLIO NOW Campaign
Past District Governor of Rotary D 9940 - Mr Pat Waite
18.30 **Socialize – rest of the evening free**

Saturday 13th

- Registration**
09.30 The year in retrospect – Edith Morris and Telling Our Stories
10.30 Morning Tea
11.00 Annual General Meeting
11.30 **Opportunities at Rotorua's QE Health** – Peter Sharplin – CEO
12.30 Mix and mingle during finger food lunch
13.15 Around the Support Groups – 3 minute Reports begin
13.30 **Health Challenges** – Chaired by Dr Liz Falkner – Life Member
(a) **Pain** – Dr Lorna Fox – Taranaki Base Hospital Pain Clinic
(b) **Sleep Apnea** – Jeremy Morris – Sleeptech
(c) **Foot care** – Carleen Gibbons – Podiatrist
15.15 Afternoon tea
15.45 Our Stories and Reports from the Support Groups continue
17.00 Free time
18.30 **Conference Dinner** with Guest Speaker – Roger Tonkin
Taranaki Personality, Car Enthusiast and Post Polio member
Nightcap

Sunday 14th

- 09.00 Q & A (but not Paul Holmes) Our Stories and Support Groups
10.15 Morning Tea
10.45 Ending Polio – PDG Rotarian Barbara Williams
11.15 Concluding Address – Edith Morris

Presenters at Conference 2011

Peter Sharplin



I was born in Rotorua and educated at Waikato Univeristy. I worked for 7 years in Wellington with the drug agency, Pharmac, before heading overseas and working for a further 7 years within the pharmaceutical industry.

In 2008, I returned to Rotorua with my wife and 4 children, consulting for a while for the local pharmaceutical industry before the opportunity arose to join QE Health in late 2010.

The role of General Manager at QE Health seemed to jump out at me as an amazing challenge and experience. The core role of QE Health is a rehabilitation service which no other health services can match, especially for Post Polio Syndrome, yet the organization finds itself in difficult waters. Parochial institutional arrangements for funding, allied with an over emphasis on surgery, are to my mind, the two reasons for the difficulties QE Health finds itself in. The solution involves a clear focus on rehabilitation and a forward approach to re-engaging with local, regional and national funding agencies. In addition, there are new services we can develop eg: a pain service, stress management programs and obesity/diabetes rehabilitation. We will follow through on these initiatives but will also keep at the forefront of our efforts – the core role of QE Health in rehabilitation, including for Post Polio Syndrome.

Pat Waite



Originally from Stratford Pat is married to Melva and together they have 4 sons and 5 grandchildren. They currently live in Tawa which has been their base for the past 30 years. They have had various terms living in Tokyo, Auckland, Dunedin, Christchurch and Sydney with a banking career with BNZ, National Australia Bank, Trust Bank and Westpac. In later years Pat was CEO at Public Trust. In his professional career he was NZ President of the NZ Institute of Chartered Accountants in 2003 and a Governor for Rotary International 2007/8. Currently he holds appointments with Board Governance and Risk Committees of major Government entities including NZ Treasury and Parliamentary Services and private director positions.

He is a trustee of several charitable entities including Mary Potter Hospice Forever Foundation and Skylight Trust as well as actively involved with Rotary both at a local and international level.

Pat and Melva have participated in two polio immunization programmes in India – January 2009 in Firozabod, Agra and in January 2011 in Delhi where they led a team of 32 Rotarians and partners. During this programme they spent time with Rotary Clubs supporting literacy, health and skills training as well as immunizing children in the poor areas of Delhi. One of the highlights for them was visiting St Stephens Hospital in Delhi which has a polio ward, and seeing the amazing work that Dr Mathew Varghase is leading with Rotary support.

Shirley is a Hero



Shirley Hazlewood, PPSS Board Member, holds her Hero Medal.

Shirley, president of the Taranaki group, was recently awarded the Rotary Paul Harris National Fellowship for her contribution to society. This is another honour for Shirley (the list is extensive) in recognition of her work with disabled support groups.

Well done! We are delighted for you. ☺

Dr Bruno says ...

Sleep Right All Night

The majority of polio survivors have disturbed sleep due to pain, anxiety or sleep disorders such as sleep apnea or twitching muscles. However, you may not be aware that you stop breathing or twitch. If you awaken at night with your heart pounding, anxiety, shortness of breath, choking or twitching, or if you awaken in the morning with a headache or not feeling rested, you need a sleep study. "Post-polio fatigue" may be due to a treatable sleep disorder.

Turn Up the Heat

Polio survivors have cold and purple "polio feet" because the nerves that control the size of blood vessels were killed by the poliovirus. Actually, your nerves and muscles function as if it's 20 degrees colder than the actual outside temperature! Cold is the second most commonly reported cause of muscle weakness and is the easiest to treat. Dress in layers and wear socks made of synthetic fabrics like breathable fiber polypropylene that hold in your body heat.

Say No to Drugs, Unless ...

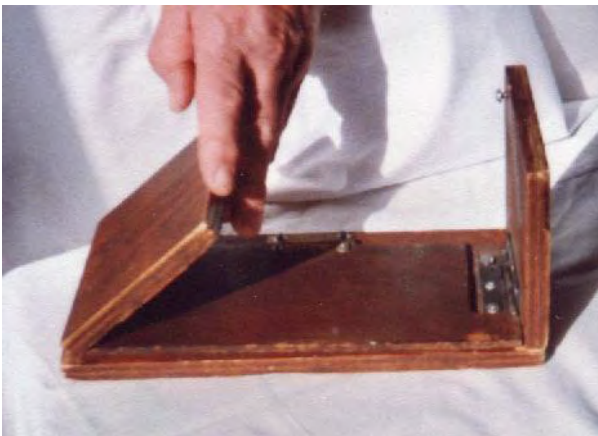
Five studies have failed to find any drug that treats PPS. And no studies show that herbal remedies or magnets reduce symptoms. Don't think that you can apply a magnet or pop a pill to make your PPS disappear. Pain, weakness and fatigue are not-so-subtle messages from your body telling you that damage is being done. Masking symptoms (with magnets or morphine) will not cure the damage. However, *two studies have shown that polio survivors are twice as sensitive to pain as everyone else and usually need more pain medication for a longer time after surgery or an injury.*

Homemade Footrest

Putting your feet up may not be possible in all situations, but some people find chairs too tall to sit on them comfortably.


Here are two photos of an easily foldable footrest – one that can easily slip into a shoulder bag – and which may make life a great deal easier.

Thanks Dorothy for sharing this practical assistive device.



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For Information and Bookings



PharmaLight (2006) Ltd Trading as Eco-Friendly Adventures Wait

According to this business Segways are a safe and reliable mobility aid for those with disabilities. I tried one for 10 minutes, with mixed results. The machine was stable, but my polio leg ached afterwards – probably because I was trying too hard! Ed

From the President's Chair

Winter brings colds, chilblains, hot soups, weight gain and a caution to watch your step on slippery paths. The more positive side of Winter is staying warm with a good book, a DVD movie and reading this issue of our newsletter.

The AGM and Conference is coming up and now is the time to be making plans to attend. What a great line up of topics we have to help us live well with polio! Delegates from Whangarei to Dunedin have already booked.

Congratulations to Shirley Hazlewood for her being awarded the Paul Harris Fellowship by Rotary NZ. Rotary and the End Polio Now Campaign will feature on the Friday evening of Conference.

Queen Elizabeth Health in Rotorua are making an effort to simplify the referral process for polios to participate in their programme. The manager of QEH will speak at conference about future plans.

On behalf of the Board of Management I travelled around our support groups in the lower North Island in March. It was an honour meeting our members and new people at these six meetings. Two groups have successfully re-activated their meetings with good attendance. My personal thanks to Board member Diane Mathews for her untiring efforts to attend, encourage and follow up each of the six support groups.

It is not a time of decrease for our PPS Society, but a time of expansion.

This was evident in the Super City Auckland PPS group meeting in May. There is the potential to start meetings in West Auckland and the North Shore in the next few months.

In March I presented a talk on "Ageing with a Disability" at the Waikato DHB Agewise Seminar. I used PPS as the basis for my talk using a clear power point presentation.

I used some of the same material for a presentation at the NZ Orthotic and Prosthetic Association's National Conference in Taupo in May. I outlined PPS, the ongoing need for braces and custom made shoes, and our recommendations to Orthotic providers. We are voicing our needs and being heard. There is still much to do in this area so we need your feed back about improvements, or not, from your regional orthotic services.

New pamphlets have been published in the last few months and are available to be distributed on request for you, your support group, your doctor, waiting rooms, pharmacies, libraries and for family members to read.

Keep warm and well,
From my wheelie friendly chair



Edith
0800 476 546
info@postpolio.org.nz

Regional Events

Nelson

Top of the South

Hello everybody,

Winter seems to approach ever faster so I trust all is well with you out there. Maybe daylight saving stayed too long?

Edith has sent us a copy of the report to parliament on childhood immunisation, a very comprehensive document of 38 pages and very appropriate as we approach world immunisation week of 23rd April until 29th April. I have it available should you wish to see it so please let me know. The Nelson DHB wish to include us in some media or social promotion but I have yet to be told what form this will take. [Today is 16th April so it doesn't give us much time!]

We report with sadness the passing of Audrey Lane of Wakefield, a long-time member of our group, and we send our deep sympathy to all her family.

Our mid-winter luncheon will be again at Brightwater Motor Inn as it is convenient for access and they always give us a very nice meal so as follows:-

Brightwater Motor Inn,
Saturday, 25th June,
12.30 pm.

Please reply to Rex [547 7043] or Jenny [545 1030] by Wednesday 22nd June if you are coming. We do hope you can come and enjoy our special time together. Some of us are becoming limited in what we can do so let's get out and do this while we are able. Keep well and warm this winter.

Regards to all from Rex Wastney and Jenny Kissane.

Wellington

On 16th March, ten members of our original group and one new member, met for the first time for over a year.

We met for afternoon tea in the Aquatics Centre Cafe in Kilbirnie and were delighted to welcome Edith Morris and her husband, Noel, who had come to talk with us.

We were able to share our concerns over the difficulties that we have had in keeping a group going in Wellington. Edith was very supportive and able to give us some ideas for re-developing a group that would, once again, be able to meet on a regular basis.

As a result of this encouragement from Edith and Noel, Philippa and I have planned a meeting to discuss suitable venue, contacting old members, and attracting new members.

Edith and Noel also brought us up to date with the current projects being undertaken by The National Board of the Post Polio Support Society, in particular the discussions that have been going on with regard to a national centre of expertise for all New Zealanders.

We appreciate the effort that Edith and Noel made to travel to Wellington to meet with us as well as to visit so many other local groups within a short space of time. They must have been very tired by the time that they got home. Thank you, Edith and Noel. It was a pleasure to meet you both. Watch this space for news of a new Wellington support group very soon!

Claudia Mushin
contact numbers
04 389 5586 or 021 543 285

Manawatu

Manawatu Standard 6/4/11

Plans are underway to reform a polio survivor group in Manawatu.

The catalyst was a strong turn-out for a public talk by Edith Morris, the new president of the Post Polio Support Society of New Zealand, in Palmerston North last month.

Meeting convener Raylee Murphy said the society was "delighted" to have around 45 people turn up.

"A letter will soon be going out to everyone who attended, inviting them to another meeting where we will decide whether we want to form a proper group." She said that for several years now there had been an informal group operating with only occasional meetings.

However, many of the people involved in earlier years were now housebound.

New Zealand has 23 support groups for survivors of poliomyelitis, a frequently fatal disease which affected thousands of people up to the 1960s when vaccines were introduced.

Mrs Morris, who was on a tour of post polio support groups in the lower North Island, told the Palmerston North meeting the national society had 600 members.

However, the society believed New Zealand could have as many as 5000 polio survivors.

With poliomyelitis being eradicated by vaccines in the 1960s, there had been a tendency for the community to think the problem was over.

However, many polio survivors developed new symptoms 35 to 45 years after the initial attack.

Because many of the symptoms mimicked problems associated with ageing, they often went undetected.

People who had polio have generally striven to become productive and independent, Mrs Morris said.

"Many are noted for over-achieving after their efforts to overcome early disability.

"Patients now need to learn how to conserve energy by pacing themselves."

During the acute polio stage, nerve fibres supplying muscle died.

The patient's later attempts to live a "normal" life put strain on the remaining fibres which then began to wear out in later life when there were no reserves left.

Because the symptoms were so obscure, many polio survivors had to "educate" doctors who had no experience of the disease or its debilitating symptoms second time around.

More information at postpolio.org.nz.

The Signs

Typical symptoms of post-polio complications:

- ⤴ Deteriorating muscle function
- ⤴ Joint and muscle pain
- ⤴ Intolerance of cold or heat
- ⤴ Difficulty in swallowing
- ⤴ Breathing problems
- ⤴ Sleep disturbances
- ⤴ Muscle twitching – including restless legs
- ⤴ Fatigue
- ⤴ Anxiety and depression
- ⤴ Greater risk of falling.

<http://www.stuff.co.nz/manawatu-standard/news/tribune/4853527/Understanding-polio>

Christchurch



Autumn colours are here and the thermometer confirms that winter is on the way. And it could be a winter to remember in Christchurch with queues at the portaloos, perhaps, or leaking roofs? Thousands of people with chimneys down have converted to electric heating; will the power supply facilities cope?

Spirits are high among our members here though and a good number turned out for this month's meeting and also for a bus trip that took us out to Lincoln University for lunch, with a nice rural tour on the way.

There's more to come too, with at least two more bus trips planned to brighten the winter months. We are sad to learn that popular members Jim and Dulcie Furneaux have had to abandon their badly quake-damaged home and now live in Wellington.

The photo shows members relaxing in the Lincoln grounds following the lunch.

George Ross

Eastern Bay of Plenty

The Eastern Bay of Plenty has experienced its share of wild weather events in the eighteen months for which I have been the Post Polio field officer for the area. However, the resilience of the

people means that only one support group meeting was cancelled in this time. A layer of silt on the ground around the Disabilities Resource Centre Trust in Whakatane, where we hold half of our meetings, would have been treacherous for our Post Polio's. Also the few who attend from out of town were restricted by slips covering main highways.

In May of this year, we were invited to do a presentation on Post Polio Syndrome to one of the local Rotary groups. A Powerpoint presentation covering the history of Polio in New Zealand and Post Polio Syndrome has been developed for these occasions. The invitation was a result of the visit to Whakatane by the cyclists who travelled the length of New Zealand raising money for the Rotary "End Polio Now" campaign. Two of our Polio survivors had intended to come to talk of their experiences with Polio and Post Polio Syndrome, but due to unforeseen circumstances they were unable to attend. The presentation was well received and many questions were fielded about such things as the rates of immunisation in New Zealand. A member of this Rotary group is to attend a future meeting to talk of the Rotary "End Polio Now" programme.

Dale Hikuroa
Post Polio Liaison Officer
Eastern Bay of Plenty

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, and 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 to whom the Society expresses its thanks.



Editorial

E H T O L C N O T T O C M A N
 C K E L T T U H S G N I Y L F
 O L E N Z F C G Z S L C D S P
 N A L V S J L E L I T X E T C
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 A T O M I C B O M B M Q C R U

Agriculture
 Atomic Bomb
 Cotton Cloth
 Cotton Seeds
 Edmund
 Flying Shuttle
 Industry
 Jonas Salk
 Nuclear Energy
 Radar
 Textile

Albert Sabin
 Cartwright
 Cotton Gin
 Economic
 Eli Whitney
 Forecasting
 John Kay
 Military Needs
 Poliomyelitis
 Social Needs
 Vaccines

A group of 11 year olds were solving this wordfind in one of my classes recently. They could pronounce all words except poliomyelitis, which they stumbled over (understandably). It became obvious that they had never heard the word before; and they certainly did not know about the effects of polio. I explained that polio was the reason I limped. It sort of went over their heads as they looked at me in a glazed way.

We need to be grateful they don't need to experience polio. We also need to increase awareness, and continue to peddle the immunisation message whenever we can.

David

Should parents be paid to immunise?

25 March 2011

The Ministry of Health should look into paying parents to encourage them to vaccinate their children, a report into New Zealand's lagging immunisation rates says.

The proposal is one of 30 outlined in a parliamentary report released recently following a health select committee inquiry into improving rates of childhood immunisation.

New Zealand's immunisation rates against deadly diseases such as measles are poor compared with other developed countries.

Only 88 percent of children are fully immunised by the age of two, which falls short of the 95 percent needed to ensure the population is safe from disease.

The report ruled out making immunisation compulsory but directed the Ministry of Health to consider immunisation incentive payments to parents, or linking existing parental benefits to immunisation.

The current incentive scheme offers payments to primary health organisations for reaching certain immunisation targets but no direct payments to parents.

In Australia, parents on any income are eligible for two payments of \$A122.75 (\$NZ166.91) if they ensure their children have met immunisation schedule requirements by certain ages.

There, immunisation rates of one-year-olds increased from 75 percent in 1997 to more than 90 percent in 2004. However, the rate drops to 83 percent by the time children are four.

Immunisation and child health experts in New Zealand are reserved about the incentive proposal.

The report said immunisation rates for under-twos had improved markedly in recent years but made a number of suggestions to strengthen existing immunisation programmes, including:

- ▲ The Ministry of Health immediately adopt a 95 percent immunisation target for all under-fours and improve the national immunisation register;
- ▲ the ministry hold district health boards accountable by aligning funding and contracting arrangements to immunisation rates;
- ▲ communications about immunisation be tailored to parents rather than organisations; and
- ▲ the ministry implement the IAC's "six star plan", which aims to strengthen and expand existing immunisation programmes at an estimated cost of \$2.14 million.

Health select committee chair Paul Hutchison said immunisation was a highly effective strategy for preventing infectious diseases but there was no silver bullet.

"For too long completion rates of immunisation for New Zealand children have been unacceptably low and I am optimistic the select committee's recommendations will be taken seriously," Dr Hutchison said.

Ministry of Health acting manager of immunisation Kim Albrecht said the Government had 90 days to formally respond to the report.

"The ministry's views will be considered in preparing that response, and we will be able to comment once this process is complete."

<http://www.nbr.co.nz/article/parents-should-be-paid-immunise-report-nn-89243>

Brain Day in Auckland

In March, at the Brain Day Community Expo, our Post Polio Support Society had a colourful stand displaying pamphlets, posters and our banner.

Members with polio “manned” the stand and were ready to answer any queries and to talk about polio. Board member John Forbes from Hamilton, Malcolm Nye and his daughter from Auckland, Mike Williams and John Lacy from Wellington all took turns relieving Anne Mace at the table and handing out material.

Two newly printed informational pamphlets, one a postcard, and the other a general outline of Post Polio Syndrome were pass out to the general public. 3,000 visitors viewed the various stalls, and it was an excellent environment to bring awareness of polio and PPS.

When asked if their children were immunised against polio, it was surprising to hear the number of people who had no idea whether they were or not.

Malcolm and Janice Nye

Comments

- ⤴ There were absolutely oceans of people, tons of children and their parents.
- ⤴ The best atmosphere and best attendance in the 6 years of running Brain Day.
- ⤴ Everyone manning the stand thought it was very worthwhile being involved in.

Thanks to Anne Mace and team for a well planned and exciting event.

Latest pamphlet on Post Polio Syndrome

Anne Mace, vice-president, arranged for an excellent pamphlet about Post Polio Syndrome to be printed in time for Brain Day in March. This pamphlet “Did you have polio?” was widely distributed at that event and continues to be in demand by our board members and support group leaders.



The great thing about this pamphlet is that it covers extra information not included in our previous ones: things like: nutrition, having a spiritual base to help with daily living, keeping a sense of humour and many other aspects. It is colourful and lightweight.

Production was generously paid for by the Freemasons Roskill Foundation and we thank them for their assistance and the printing of 8,000 pamphlets.

These are available by request from the secretary-treasurer

**JB Munro
ph 03 489 1995**

Restless legs

Restless legs syndrome (RLS) or Wittmaack–Ekbom syndrome is a neurological disorder characterized by an irresistible urge to move one's body to stop uncomfortable or odd sensations. It most commonly affects the legs, but can affect the arms, torso, and even phantom limbs. Moving the affected body part modulates the sensations, providing temporary relief.

RLS sensations can most closely be compared to an itching or tickling in the muscles, like "an itch you can't scratch" or

an unpleasant "tickle that won't stop." The sensations typically begin or intensify during quiet wakefulness, such as when relaxing, reading, studying, or trying to sleep. In addition, most individuals with RLS have limb jerking during sleep, which is an objective physiologic marker of the disorder and is associated with sleep disruption. Some controversy surrounds the marketing of drug treatments for RLS. It is a "spectrum" disease with some people experiencing only a minor annoyance and others experiencing major disruption of sleep and significant impairments in quality of life.

Vaccination

From a 2011 Parliamentary Report of the Health Committee concerning vaccination in NZ

Table 4: Polio disease and vaccine risks

Disease	Risk from disease	Risk from vaccine
Highly contagious gastrointestinal infection for which humans are the only reservoir	While many infections cause no symptoms, about one in 20 hospitalised patients will die and half of all surviving patients are permanently paralysed.	Local redness (one in three); pain (one in seven); swelling (one in 10); fever, crying, and decreased appetite (one in ten)

Directory

Information about membership and local support groups

Free phone 0800 4 POLIO (0800 476 546)

Website: www.postpolio.org.nz

Email: info@postpolio.org.nz

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email info@postpolio.org.nz

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Post Polio Support Society NZ (Inc),
PO Box 249
Oamaru 9444

Secretary-Treasurer:

JB Munro
120 Factory Road
Mosgiel 9024
Ph / Fax 03 489 1995
email jbmunro@xtra.co.nz

2011 POST POLIO CONFERENCE

NEW PLYMOUTH



**POST POLIO SUPPORT
SOCIETY NZ (INC)**

Friday, Saturday, and Sunday morning August 12th to 14th 2011

Registration Form to be completed and returned by 31st JULY 2011

Name: _____
Mr/Mrs etc Surname Preferred greeting name or First name

Address: _____

Phone: _____ Email: _____

Have you had Polio **Yes / No**

If yes **What year** _____ **and Location:** _____

If not a Polio Survivor what is your interest? (Carer, Family, Job) _____

Please circle Yes or No in response to the next five statements:

I plan to attend the Friday early evening Official Opening	Yes or No
I plan to attend the Saturday Morning Session	Yes or No
I will stay for lunch at a cost of \$20 (Pay at the reg. desk)	Yes or No
I plan to attend the Conference Dinner on Saturday evening at a cost of \$40 each (Please pay at the Registration desk)	Yes or No
I plan to attend the Sunday morning	Yes or No

Please accept my donation to help defray Conference expenses: \$ _____

It would be appreciated if you could advise your travel arrangements, especially by air as we will have transport available from the airport. Please advise your ETA and ETD as follows:

ETA: Day: _____ **Time:** _____ **Flight No.** _____

ETD: Day: _____ **Time:** _____ **Flight No.** _____

NB. Accommodation and travel bookings are the responsibility of each delegate attending. However our Taranaki organising committee are happy to organize your preferred accommodation. For your information - Accommodation charges for an Executive Room at the Quality Hotel Plymouth International are \$135 + gst (\$155.25) per night.

Should you have questions or queries regarding accommodation or registration, please do not hesitate to contact Marie Frewin Ph 06 753 5118, Email: m.frewin@xtra.co.nz

Please post this form when completed to:

**Marie Frewin
Post Polio Conference
C/- 1 Cornwall Street
Brooklands
New Plymouth 4310**

Conference 2011

POST POLIO SUPPORT SOCIETY

NZ Incorporated

ANNUAL MEETING & NATIONAL CONFERENCE

The Quality Hotel Plymouth International

Friday 12th August to Sunday August 14th 2011

“Living well with Polio”



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