



# Polio News

Post Polio Support Society NZ (Inc)

November 2008

## Conference 08 – A Raging Success



*Coffee break during the first day. A time for refreshment, meeting new faces, and catching up with friends.*



*Jega enthralled the audience with her understanding, skill, experience, and empathy in dealing with polios.*



*David Guest from Enable NZ is introduced at the start of his presentation.*



*Three brave volunteers get put through their paces in the hydrotherapy pool, with Jega directing the activity.*



*Jega shows her skills in the physio facilities of Palmerston North Hospital.*

The two days were filled with dynamic presentations from highly qualified individuals. They all exuded enthusiasm for their subject. Combined with excellent facilities and great catering this made for a highly successful annual Conference.

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# Conference '08

## Jegasothy



Jega gave a spirited sequence of presentations on her work in Perth WA, ranging from how the Assessment Centre was established to how individuals are assessed at the centre. Her work is to assess individual patient's needs, and then to refer the patient to the most effective services available. So each person gets a customized programme suited to their individual situation.

Jega showed her mettle on the second day when she assessed three volunteers. Some of the questions expressed profound insight...."Was it pain or muscle weakness that caused you to fall?".... indicating whether pain control or mechanical assistance was the issue. She expertly told if existing muscles could be strengthened by simple exercise; and what the benefit of the outcome would be (eg better stability). Her emphasis on starting for short periods (as small as 15 seconds) a day and building up to longer times showed an empathy with the limits of those with disability. Exercise should never create fatigue. Finding the balance between the positive benefits of being fit, and overuse which causes fatigue, is the challenge facing all polios and their support network.

Jega spent considerable effort in the hydrotherapy pool demonstrating how effective strengthening exercise could be achieved in the buoyant medium.

## Dr Jurriaan de Groot



Dr de Groot gave an engaging presentation about the medical aspects of PPS.

The following factors are often called the Late Effects of Polio:

1. Biomechanical dysfunction
2. Orthopaedic discrepancies
3. Overuse injuries
4. Ergonomic inefficiency
5. Functional deterioration with time and age

Combined with the overachieving personality of a typical polio survivor, one or more of these factors can make life less than 100% enjoyable.

Jurriaan described Post Polio Syndrome as ..... "an otherwise unexplained constellation of symptoms in a patient who had paralytic polio, and may include:

1. New muscle weakness
2. Muscle and joint pain
3. Fatigue
4. New muscle wasting
5. Heat or cold intolerance
6. Swallowing, breathing or sleep disturbance"

Jurriaan's presentation showed a graphic sequence of how polio affects the motor neurons, then how they recover, and finally how they degenerate to cause post polio syndrome.

# Conference '08

## David Guest



EnableNZ supplies equipment for those with disabilities. David presented an outline of how EnableNZ helps.

Some of the newer equipment pushes the boundaries of traditional thinking, like this all-terrain wheel chair. Sadly, it's not yet available here.



Enable run a Returned Equipment Store, where serviceable equipment is returned once it is no longer needed. It then waits until re-issued to another user.



## Melanie Trevethick



"It is not wealth one asks for, but just enough to preserve one's dignity, to work unhampered, to be ... independent."  
*Somerset Maugham.*

Melanie used this quote to point out that if you are going to be sick in NZ then you had better be wealthy. This is because the support for those suffering disability due to ill health is woefully under funded.

When compared to the funding that ACC receives this becomes intolerable. ACC is a world class insurance scheme whose objective is to rehabilitate the accident victim. ACC is funded up to \$7 000M; the Ministry of Health funds EnableNZ up to \$60M. The discrepancy is obvious. Also, the Ministry of Health produces dependency, rather than rehabilitation leading to independency.

Melanie went on to say that New Zealand is the only country in the world with a two tier system that actively distinguishes between disability caused by accident, and disability caused by ill health. She has made it her mission to attempt to correct this dreadful imbalance, through legal and political means.

Melanie's speech was extremely well received at the Conference Dinner.

## Ray Wilson passes the baton on



*It is always sad to see familiar incumbents retire from active duty. However Ray assures us he will continue to contribute to the society*

### Ray's Valedictory

Greetings All;

I guess this is what is referred to as a 'Swan Song' so I will try to avoid the teary eye if I can.

I assume by now that you the members will be aware that the Society has a new 'President' and what is more a member of the 'Fairer Sex'.

I took delight in Pinning my Badge of Office on Edith Morris when the announcement was made during the Friday Evening Conference Dinner. I also wished her well in the challenge she will face, and pledged my total support to her whilst the transition takes place.

To the new Members of the Board the challenge will always be with you to seek better support from those persons who hold sway when it comes to fairness and understanding of our member's plight.

As I can now unwind a little – I still have the Society and it's future at heart. I guess I will always be interested in the goings on and eagerly await the Newsletter to catch up on the latest news.

I must pay tribute to those who have served with me in the Management Team, and thank them for their loyal support to me as President. It is not always possible to have harmony in situations like a Board of Management but everyone always had the Society in mind when the crunch line came.

I as President used to look to the Board Members to be my eyes and ears with regard the Society's group/branches closest to their place of residence. Maybe that should have been a two way street with the groups/branches keeping in touch with their nearest representative. These members are the 'Society's' life blood and need to be fostered to keep them active for as long as possible. In hindsight the only way I see to do this is by phone contact, and that that cost should be borne of the Board of Management.

I was honoured to be able to present to Dr. M.E. (Liz) Falkner her Life Membership Award during the Friday Evening Dinner. It was a thrill to see her face light up as the secret had been well concealed for the past three months. She told me in an email message that her husband Terry had got a bigger kick out of it than she herself had got. It was being installed on the wall in the Dr's Surgery for all to view. Thank You Liz for your tremendous contribution to the Society its past and future.

Our Time in Palmerston North last September with 'Jega' at the helm was without doubt the most informative I have had the pleasure of attending. Jega, complete with her overheads and physical personal descriptions of disability caught

your attention straight away. Coupled with the two sessions at the Manawatu Hospital Rehabilitation Centre – thanks To Dr Jurriaan de Groot, and his staff at the Rehab centre who gave of their time for our benefit - having sessions in the gymnasium and the pool being of special interest to those with a disability and how it could best be managed. Just as an aside to this, Jega's session in Dunedin saw JB with his foot bare, looking at his walking gait and how it could be managed.

Thank You Jega – but please don't be too long before you come back to this country. I am sure with your integrity and understanding a way could be found to repeat what you have developed that's working so well in Perth W.A., here in New Zealand.

My thanks also to David Guest – Enable New Zealand, who used his time to explain their organisation and the process of seeking access to aids for persons with disabilities – although I sensed at times some disbelief by the listeners to his theories.

Never the less his subject was well received by the audience he was speaking to.

To Melaine Trevethick, who was our Guest Speaker at dinner on the Friday evening, I believe that you have the determination to win your cause, and in the process maybe aid others who have been targeting similar such issues for many years. "Good Luck "

I will keep a watching brief from home as the Society enters its twentieth year of operation.

Good Luck to you all

Stay Safe & Live Happily.

Ray(mond) L. Wilson (Life Member)

## President's Message

What an honour it is for me to be elected President of our Society.

I have a passion for lifting up the profile of our organisation and promoting our cause.

Des Crabb is our new Vice President and I can rely on his wise and steady influence. JB Munro remains as our hard working secretary treasurer.

Our board of management are the eyes and ears of our society and can help identify how best we can serve and encourage you. I look forward to developing closer contacts with you.

Thank you for your confidence in me.

My sincere regards,

Edith



## Post Polio Support Society at the Health and Disability Expo

We had a very good preparation and assistance from The Expo committee in organising our stand at the Expo. We were able to select the position that we had and it was right in your sight as you came through the door.

The Waikato members were very supportive and willing to give of their time and I would like to thank them very much. The Stand was designed and assembled by Noel Morris husband of Edith Morris our new President of the Post Polio Society and erected by Linda their daughter.

We had many visitors with many questions. One in particular asked "What is Polio?" As there were two survivors on the stand at the time we were able to answer her question.

From the Statistics I have learned that 3000 attended over the two days and we had 88 stands. The stands covered a great deal of health and disability organisations with some very good displays.

The Toyota group had a very impressive vehicle on display that would enable a wheelchair to drive up a small ramp to sit in the rear of the car.

The whole atmosphere was very comforting and informative and friendly. We would agree that it should be a yearly event.

Laura Ladkin



## A Little Bit of History

Hilary Koprowski was born in 1916 in Poland. At the age of 12 he entered the Warsaw Conservatory of Music. He received his medical degree from the Faculty of Medicine at Warsaw University in Poland. He also received music degrees from the Warsaw Conservatory and the Santa Cecilia Conservatory in Rome. He chose scientific research as his life's work.



Koprowski created the world's first polio vaccine, based on oral administration of attenuated polio virus. In researching a potential polio vaccine, he had focused on live viruses that were attenuated (rendered non-virulent) rather than on killed viruses (the latter became the basis for the injected vaccine that was subsequently created by Jonas Salk. Koprowski viewed the live vaccine as more powerful, since it entered the intestinal tract directly and could provide lifelong immunity, whereas the Salk vaccine required booster shots. Also, administering a vaccine by mouth is easy, whereas an injection requires medical facilities and is more expensive. Koprowski's vaccine was taken by the first child on February 27th 1950 and within 10 years was being used on four continents. Albert Sabin's attenuated-live-virus polio vaccine was developed from attenuated polio virus that Sabin had received from Koprowski.

## Regional Events

### Waikato

Trish Johnson, a practising physio, gave a riveting presentation to the fifteen who attended our last meeting. Trish deals a lot of the time with sports injuries, but her mother, also a physiotherapist, dealt almost exclusively with polios! She emphasised that the specialist knowledge is being lost, and her younger colleagues now have no contact at all with polios. This is an amazing change in the span of one generation!

Trish talked of the way the polio virus attacked the motor neurons, and not the sensory neurons. Polios can still sense touch and temperature (unlike paraplegics). But the motor neurons get overused in polios and give up. Incidentally, motor neurons also give up as a natural part of aging, so polios today are fighting a war on two fronts. This can lead to PPS, indicated by such things as fatigue, muscle pain, joint pain, muscle weakness, cold intolerance, sleep disturbance (wake up and hurt), and some activities no longer being possible (climbing stairs, getting dressed, etc)

The impact of Trish's presentation showed in the depth of experience shared by the group at question time. The frustration at being told by medical people that all problems were due to advancing age got mention. The group felt really heartened that Trish knew differently.



*The group listens intently*



*Trish Johnson addresses us*

Thanks to Edith and Noel Morris for hosting the event in a wheelchair-friendly home; and to Laura Ladkin for organising the event.



*Trish, Edith, and Laura*

### Nelson – Top of the South

Hi everybody,

Well, it's that time of year again when busyness just got busier! No news of moment from here apart from many of our members having ongoing problems with mobility and personal care issues. Special get well wishes to Kathy Standen in Golden Bay and also Ian Frost who have both been hospitalised.

Our Christmas luncheon will again be at the Brightwater Tavern as this provides easier access for all.

Continued ...

**Brightwater Tavern, Saturday, 29th November, 12.30 pm.**

Please reply re your attendance by 24th November to Rex Wastney [5477.043 ] or me on 545.1030.

May our Nelson group wish you one and all season's greetings and a healthful and happy 2009.

Jenny Kissane and Rex Wastney.

## Christchurch

All those beautiful daffodils around our city have come and gone; trees have blossomed and then turned green so clearly Christmas can't be long away. In a way it has been a sad year with the loss of several members and this, coupled with the advancing age of remaining stalwarts, has seen a gradual decline in attendances at our monthly meetings from around 35 a while back to more like 25 currently.

There is still enthusiasm among the regulars however and, dare I say it, any event that promises a meal as part of the package can still draw a bus load of starters. It's sad, too, to read of the resurgence of polio incidence in, notably, Nigeria and India when, a few years ago, permanent eradication was so nearly achieved. Should we, as a national group, be urging the authorities to not give up on worldwide campaigns to win the battle?

What have Christchurch folk been embarked on recently? Well, our vacationers have just returned from their annual week of frolics at Hanmer looking tanned and rejuvenated and a month earlier we had a pleasant expedition to a private museum in North Canterbury to view their colonial relics and savour a home-cooked hot lunch. A couple of photos show some of the familiar items on display.

A very Merry Christmas to all.

George Ross



## Otago

What a great conference this year. The spin off for Otago was enormous. We found Jega an inspirational speaker with her practical politics for obtaining the specialist help Post Polios need and for her very down to earth, caring approach to treatment. She discarded any extraneous medical conditions and consigned them to the relevant medical practitioners so that she could concentrate entirely on the late effects of polio. She questioned each patient carefully and made no assumptions or decisions until she had the full story. Only then did she offer very decisive advice.

This approach was reinforced when Jega later spoke to a group of about thirty members from Otago at an afternoon tea meeting in Dunedin. Most people went away with a better understanding of their condition and what to do about it.

Diane Body, a Dunedin Hospital physiotherapist who attended the Conference with us, has already been pro-active on her return. She has shared her knowledge with several groups already. Firstly with students at the School of Physiotherapy, then with a group of doctors, nurses and undergraduates and still to come, with the Dunedin Hospital physios.

At our meeting last Saturday (held in a café for a change ) Diane spoke to our members of the late effects of polio and included a lot of very practical advice. She followed this up by responding to individual inquiries. We greatly appreciate the time and effort she has given to educate others on our behalf.

Diane Jackson

### **Northland**

Hullo again from the far North. First our sincere congratulations to Edith on becoming our new President and to her new committee. We wish them all the

best for the forthcoming year and the tasks involved. Also we would like to acknowledge the great work that Ray has done over the past years and wish him and Iris health and happiness in their retirement.

Our August meeting was our A.G.M. and as expected no changes were made to our committee, all members were re elected unopposed! and so we continue as best we can for another 12 months.

One of our members, Mike, spoke to us about his work as a volunteer helper at the Whangarei Citizen's Advice Bureau (C.A.B.) It was interesting to hear about the many facets of the work there and the number of interesting people they deal with.

Our latest meeting was an enjoyable luncheon meeting at a popular central cafe in Kamo where 14 members (including 3 from Kerikeri) gathered together to celebrate spring, after a long wet winter, and to enjoy good food and fellowship.

Now the countdown is on again till Christmas and the end of another year! We wish you all health and happiness for the coming year.

Ruth Inglis.

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**Directory:** Information about membership and local support groups

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## 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.



*Conferring at Conference*

## Editorial

### Inspired action

Conference came together very successfully because of the hard work of those organising it. They found world renowned experts who connected with us in a very real, practical manner. Congratulations to all concerned.

Some of the points that I took home included:

1. At all costs don't fall down
2. Don't fall – it breaks bones
3. Ensure you don't fall over.

The connection between remaining independent and remaining upright was made crystal clear by Jega. A broken leg equates to a high maintenance individual who is dependent on others. And us Polios being what we are, survivors who treasure their independence, we need to avoid falling at all costs.

So I have been re-assessing a few things. Firstly, I've tried to insist (once again) that the four other adults in my household don't leave their shoes, bags, backpacks, books, laptops, etc on the floor or in the entrance where I walk. And I have been looking seriously at my footwear to see if I am getting the maximum amount of support for my drop-foot. It is my intention to make old, **independent**, bones!

I hope that other attendees also went away inspired in some way or other. There was plenty of inspiration available. I am sure everyone will agree that Jega's enthusiasm for her profession was amazing. Also Jurriaan and David obviously enjoyed making their contributions to the gathering.

Conference08 will be a hard act to follow.

Cheers  
David

## Little Helps for Little Polios and Others

*Dorothy Foster from Whangarei very kindly wrote the following article. She finds these devices useful and hopes that others will do so too.*

### **Simply made or inexpensive devices to avoid or ease painful muscles**

#### **HALF STEP**

A stable removable platform to use at kitchen bench in households where occupants are various heights. Prevents tired arms and back. Easily picked up and stored on side against wall. Can be made by handyman.

#### **Materials**

1 piece laminated 6 ply board 60 cm x 40 cm for top.

2 boards 60 cm x 9 cm x 1 cm for sides.

2 boards 40 cm x 9 cm x 1 cm for ends.

35cm stiff nylon cord 0.5 cm for handle

Felt – 2 m of 1 cm wide black felt tape

Paint or varnish, wood glue and small nails.

#### **Assembly**

1. Mitre corners of the frame.
2. Glue and nail together.
3. Glue and nail top to frame.
4. Paint or varnish sides.
5. Glue vinyl on top if desired, or paint.
6. Glue felt tape around bottom of base to prevent scratching floor.
7. At one short end bore 2 holes centred, 10 cm apart.
8. Thread cord through, tie knots inside and seal with flame to prevent unravelling.

#### **Warning**

Be extremely careful if you have poor eyesight, poor memory or poor balance. Remember whether you are on or off the half step when moving. Painting the top with contrasting colour to the floor will help.

#### **OCTOPUS**

Simple massager for lower back and thighs and other reachable places.

A small hand-held hard plastic knob with eight short legs. Available from The \$2 shop.

Gently rotate over sore or tired muscles either directly onto skin or over light clothing.

#### **LOWER BACK MASSAGER**

To loosen tight back muscles from waist to buttocks. Useful if no spouse or kind friend available. Only for users who can get down onto the floor — and know they can get up again.

#### **Materials**

1. Non-stretch cotton sock.
2. Two tennis balls - used will do.

#### **Assembly**

Tie a knot in toe of sock. Insert both balls. Tie knot above the balls as close as possible.

#### **To Use**

1. Lie on back on floor, head on cushion, feet on floor slightly apart, knees bent.
2. Lift your buttocks and position the balls centrally at base of spine.
3. Supporting yourself on your upper arms gently roll your spine over the balls upwards, downwards and even out to the hips. Don't be afraid of any graunching noise which will disappear with practice.
4. Gradually work your body downwards over the balls, moving feet to adjust.
5. To get up, roll onto side, then onto bands and knees and up.

## UPPER BACK MASSAGER

For hard to reach back and shoulder muscles. Easier to use than the floor. No helper required. Use against a wall. Wallpaper is better than a smooth door.

### Materials

1 x tennis ball.

Lower half of one pantyhose leg.

### Assembly

1. Drop ball into toe of pantyhose. Tie knot firmly as close as possible.
2. Tie a second knot for gripping at the open end of pantyhose.

### To Use

1. Stand against the wall, feet about 15 inches apart and a few inches out from wall.
2. Holding the gripper knot drop the ball end over one shoulder.
3. Leaning against the wall, gently rotate your body sideways against the ball, up and down and in small circles.
4. To change position of ball, either lift on the gripper knot or bend the knees.

## PORTABLE BED BOARDS

If your back is as sensitive as that of the Princess and the Pea and sleeping in a saggy strange bed gives you a restless night followed by a painful day, a set of portable bed boards placed between mattress and base of a single bed may help.

### Materials

6 boards 46cm x 7 cm x 1 cm

3 x 6 cm hinges with screws or pop rivets

2 metres string

Strips brightly coloured cloth

3 old socks

1 tea towel

### Assembly

1. Screw or rivet hinges to each pair of boards so they will lie flat when unfolded to fit across single bed.
2. Enamel boards for smooth insertion between mattress and base.
3. Bore a hole in one end of each set. Attach 60 cm string.

4. Tie reminder cloth to other end of string to dangle onto floor and be highly visible when packing and departing.
5. Place old sock on opposite end of each board to avoid damage when inserting under mattress.
6. Label each pair with name and phone number.
7. Make drawstring bag from teatowel for storing and discreetly carrying boards.

## BACK CUSHION WITH FLAP

A solid foam contoured back support cushion is obtainable from Para Rubber Co for about \$27. Payless Plastics have similar for about \$35. They have a removable washable covering.

To prevent the cushion from sliding out the bottom of lightweight chairs often provided at meetings, stitch a flap of material about the same size as the cushion to the lower front edge of the cushion. Drop this over the seat of the chair before sitting down. The weight of your body will prevent the cushion escaping.

If a slightly dished seat causes hip and lower back problems stitch a pocket to the centre of the flap and insert a small thin removable cushion.



*More conferring at Conference '08*

## **.Disability Commissioner?**

The Deputy Health and Disability Commissioner says a new government report could solve the problems limiting its ability to advocate for people with disabilities.

Parliament's Social Services Committee has released the results of its inquiry into the quality of services and care available in the sector.

The inquiry followed allegations of deaths, poor staffing and mismanagement at the service provider Focus 2000 - the business arm of the Cerebral Palsy Society.

The report makes 22 recommendations, including the introduction of a separate commissioner.

The chairperson of the Social Services Committee, Russell Fairbrother, says the sector is well resourced, but sometimes has a greater focus on the service providers rather than consumers.

He says an independent commissioner could improve advocacy for the disabled.

Other recommendations include establishing local area needs coordinators, to directly help disabled people get the services they need.

The Multiple Sclerosis Society says the existing Health and Disability Commissioner has been of little help to members trying to get the care they need, and splitting the role will not change that.

Deputy Health and Disability Commissioner Tania Thomas admits her office can accept complaints only about the quality of services, not access to them. However, she says the report suggests changing that.

The National Party says the inquiry has revealed systemic problems and a lack of leadership. Disability issues spokesman Paul Hutchison says disabled people have been at times afraid to speak out for fear of repercussions.

The Ministers for Health and Disabilities Issues say they will be calling an urgent meeting with key players in the sector.

## **Information Request**

My name is Barbara Elizabeth Mackay, I am 60 years young, I was born on 22nd April 1948, I have poliomyelitis I am also a client of the Centre for Cerebral Palsy WA Inc. I am also a member of the Post Polio of WA however I was not born in Western Australia I was born in Hobart Tasmania, I see myself as fortunate i can talk and walk, I now walk with the aid of a fold-up-walking frame, I do have a little bit of a speech impediment and I also use a mobility scooter. I would be interested in receiving your newsletter either through e-mail or I will let you have by snail mail address it as follows Ms. Barbara Mackay Unit D4/St. David's Retirement Centre 17-19 Lawley Crescent Mt. Lawley Western Australia, Australia 6050 and my phone number is (08) 93705708 please be aware I have an answering machine it takes a long time to cut in and it is my speaking voice. I am also writing because I am going to come to New Zealand for a holiday next year 2009 and I would like to know if any of your members know of any interesting places and accommodation for a person with a walking frame one of the places I would like to go is to the bay of islands, I also made contact with a lady called Janice she has polio and she lives over on the North Shore from Auckland if any of your members or you know her can you tell her that I lost her address unfortunately because my computer crashed because my phone line went down. Could you pass on my snail mail details to her if you can contact her. If people would like to contact me, or send me some information I would be very happy to pay postage. My email address is bem@iinet.net.au. I look forward to hearing from you and any of your members.

Thank You. Barbara Mackay

*If you can help Barbara with information please send it directly to her.*

## Pharmalink reports positive phase III results for Xepol®, a treatment for postpolio syndrome.

*Hi all,  
This arrived in my email and I thought I should forward it on to you all. I am not sure of the importance but looks to be worth a follow up.  
A comment back would be welcome from anyone who has any knowledge of this product.  
Ray Wilson*

STOCKHOLM, SWEDEN

August 26, 2008

Pharmalink AB today announces positive results from a follow-on Phase III study of Xepol®, its candidate for the treatment of post-polio syndrome (PPS). The data have shown the candidate to be effective and well tolerated with no serious adverse events attributed to the product being reported in the treated patients.

The Phase III study, involving 142 patients, is a placebo controlled, double blind trial designed to evaluate the efficacy and safety of Xepol® in PPS, a neurological pain and weakness syndrome in patients that have survived poliovirus infection. The original placebo controlled, double blind Phase III trial was six months (Gonzalez et al (2006) Lancet Neurology 5:493-500) and this follow-up period was another six months.

The follow-on results strengthen the position of this novel treatment modality for PPS by demonstrating a reduction of inflammatory cytokines in the cerebrospinal fluid and a significant reduction of symptoms of PPS while also showing that Xepol® is safe and well tolerated with few or no side-effects. Endpoints studied were pain, walking ability and SF-36 scores (a common self assessment scoring system that measures physical and psychological variables). All showed significant and clinically meaningful results. Full results are to be published in a peer review journal.

Xepol®, the first medical PPS treatment, is an injectable biologic product, administered once per 9-12 months, which down-regulates the inflammatory process in the nervous system of PPS patients. The concept and medical hypothesis was first developed by Dr Henrik Gonzalez and Professor Kristian Borg, scientists at the Karolinska Institute (Sweden). Pharmalink licensed the invention and is now working to bring the candidate towards registration.

"We are very encouraged by the outcome of the follow-up analysis as it is clear from the results that Xepol brings relief from pain and muscle weakness to PPS patients," said Johan Häggblad, Managing Director of Pharmalink. "We are very excited about this data as currently there is no medical treatment for PPS and patients in the treated group have experienced a reduction in disease symptoms after just 12 months."

"It is very rewarding to see that Xepol is demonstrating efficacy and the potential to help PPS patients," said inventor and principal investigator Professor Kristian Borg. "We are looking forward to expanding the Xepol treatment procedure following product registration."

Pharmalink is actively seeking a partner to bring Xepol® to the market. More than 1000 PPS patients have been treated with the drug and many return on an annual basis for new treatment courses. Xepol® has already achieved Orphan Drug Designation in the US and is patented in the major markets.

For further information, please contact:  
Pharmalink: Johan Häggblad, Managing Director, +46 (0)70 668 0644  
Email: [johan.haggblad@pharmalink.se](mailto:johan.haggblad@pharmalink.se)  
Web: [www.pharmalink.se](http://www.pharmalink.se) Click the Project button then click Xepol.

## Afghan Taliban back UN anti-polio drive

### Peace Day: Spokesman

KANDAHAR, Afghanistan (AFP) — A spokesman for Afghanistan's Taliban said the militia would cease attacks on UN Peace Day on Sunday and would not obstruct a three-day polio vaccination starting the same day.

The Afghan army and international military forces have also announced, after a call from President Hamid Karzai, that they would halt offensives on Peace Day, September 21.

"In respect for the international Peace Day, Taliban have issued a declaration that we are in a defensive position and we will cease attacks," a spokesman for the group, Yousuf Ahmadi, told AFP.

The extremists, who are linked to Al-Qaeda, posted a statement on their website to the same effect.

"If NATO and America and their followers respect this day for real, and avoid tricks and announce the ceasefire from the depth of their heart, the (Taliban) will also instruct to its own mujahedeen (holy warriors) to take the defensive position on this day," the statement said.

Ahmadi also said Taliban would "cooperate" with a three-day UN polio vaccination campaign due to start in volatile parts of the country on Sunday.

Vaccinators must however "keep in contact" with Taliban in areas they visit to make sure they were safe, he said.

Two Afghan doctors working on the polio campaign were killed in a Taliban suicide car bombing in the southern province of Kandahar a week ago.

The bomber attacked two marked United Nations vehicles as they travelled through a market, also wounding several civilians.

Ahmadi claimed the target of the bomb had been UN vehicles transporting "American soldiers."

The Taliban says its fighters are trying to free the country from Western "invaders." The militia's attacks kill more civilians

than troops, also targeting school teachers, health workers and aid workers. Afghanistan is one of a handful of countries that still has the crippling polio virus, with 18 new cases reported this year, all in the south and east where insurgent violence is the strongest and health workers most at risk.

Vaccinators have been unable to reach about 100,000 children in the south because of the insecurity, the World Health Organisation says.

The three-day campaign starting on Sunday is expected to reach 1.8 million children in six provinces in the south.

The United Nations confirmed it had received a letter from the Taliban about the Peace Day polio campaign.

"All statements of support for Peace Day are very welcome," spokesman Adrian Edwards told AFP.

"It's an apolitical campaign for peace and our objective in this is simple - we want to open humanitarian space for initiatives such as polio vaccination.

"And on the political side, we want to open space to have peace back on the agenda."

The Taliban were in government between 1996 and 2001, when they were removed in a US-led invasion for sheltering Al-Qaeda after the September 11 attacks on the United States.

Their fight against the elected Afghan government and its allies has claimed thousands of lives.

In a new attack, a coalition soldier and two Afghans were killed Saturday when a bombing, similar to those used by insurgents, struck their vehicle in southern Afghanistan.

## LIFE MEMBERSHIP AWARD

### **Dr M E (Liz) Falkner**

**MB, BSc (London) LRCP (London) MRCS (England)**

Dr Falkner of Masterton has been associated with the Post Polio Support Society of NZ Incorporated for twenty years.

A Polio survivor herself Dr Falkner is a General Practitioner who voluntarily has served as Medical Advisor to the Society since 2000.

She has supported the Society in many ways through radio, media articles, medical journals as well as providing strong advocacy to successive Governments and in particular the Ministry of Health and Disability.

Liz has written and co-authored publications for the Society including the popular and practical fact sheet "Post Polio Syndrome"- now due for its third reprint.

Dr Falkner was elected onto the NZ Board of Post Polio in 1991 and has been active in the interests of the Society locally and nationally ever since.

12th September 2008

## LIFE MEMBERSHIP AWARD

### **Raymond L. Wilson QSM**

Raymond L Wilson QSM contracted Polio (Infantile Paralysis) as an 8 year old in 1936. He spent several months in Dunedin Hospital and wore a spinal brace for three years and was left with a permanent wasted upper left leg.

In 1989 Ray and his wife Iris retired to Oamaru and the next year they joined the NZ Post Polio Society and the North Otago Support Group.

In 1993 Ray was elected on to the Board of Management of the Post Polio Support Society of NZ Incorporated and subsequently elected Vice President in 1997 and NZ President in 1998. He was honoured by the Queen in 2002 with the QSM.

Ray has represented the Society overseas and has visited most NZ branches and support groups. Ray has been the principal fund-raiser of the Society and through his tenacity and friendly demeanour with key people at the JR McKenzie Trust Board, the NZ Lottery Grants Board and the Duncan Trust, the Society has benefited significantly from the grants received.

The Society's 2008 Conference noted the pending retirement of Ray following his 80th birthday and was pleased to acknowledge his service, commitment and loyalty by bestowing on him **New Zealand Life Membership** for all his efforts.

12th September 2008