

Polio News

May 2007 Newsletter of the Post Polio Support Society NZ (Inc.)

Milestone for NZ Polio Society

The Post Polio movement in New Zealand is 20 years old next month and many of the movers of the founding of the PPSS at that time are still working hard for disability issues within the PPSS and in other organisations.

The PPSS got under way after Philippa Morrison and 14 others, including a GP from Napier Hospital, paid their own way to a polio conference in St Louis, Missouri, in June 1987. Back in New Zealand they saw a need for a national organisation. Before the end of that year it was heading towards incorporation with about 150 polio contacts.

Feilding was regarded as just about the earliest of the support groups -- co-ordinated then as it is now by Raylee Murphy. Doreen Chandler, now president of the separately incorporated Auckland group, was among the early movers as was Lois Campbell in Wanganui. There were many others.

The fledgling society picked up members by word of mouth and from articles in national magazines and provincial newspapers. Then as now a news sheet called *Polio News* was instrumental in helping to maintain contact between the many people and the new groups in the growing organisation.

Personal contact with overseas polio networks has stimulated PPSS over the years-- a process which is particularly active this year. Visiting Australian post-polio co-ordinator Mary-ann Liethof from Melbourne spoke to the NZ PPSS board in Wellington in March. And most of the PPSS Board go to Sydney this month for a "think tank" on the future of polio organisations on both sides of the Tasman. In her Wellington presentation Mary-Ann Liethof gave an in-depth outline of how the various Australian states structure their polio rehab networks.



PPSS President Ray Wilson and Mary-ann Liethof look over a November, 1987, copy of *Polio News*.

IN THIS ISSUE

Directory, Editorial	2	Medical/Swallowing	6	Mobility aids	11
President's report	3	PPSS support groups	7, 8	Self defence	12
Polio feet, tips and tricks	4	News items	9	News items	13
PPSS Board meeting	5	My KAFO dream	10	Media feedback	14

DIRECTORY

The Post Polio Support Society of NZ is an incorporated society dedicated to providing support for people who have had poliomyelitis. It can provide information and assistance for all polio survivors and their families, whether or not they are experiencing problems at present. For information about membership and local support group contact numbers, freephone 0800 4 POLIO (0800 476 546).

The Society's website address is www.postpolio.org.nz. The mail address is: Post Polio Support Society NZ (Inc), PO Box 249, Oamaru. Other contact details:

President: Ray Wilson, 29 Aln Street, Oamaru 9400 (Tel/fax 03 434 6405. . email rayl.wilson@clear.net.nz).

Secretary-treasurer: JB Munro, 120 Factory Road, Mosgiel 9024 (Tel 03 489 1995, fax 03 489 1996, email jbmunro@xtra.co.nz)

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. The Editor is Jim Webber, 103 Amohia Street, Paraparaumu 5032 (04 905 4148, e: ferris.webber@paradise.net.nz). 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.



JR McKenzie Trust

Editorial

What's in a slogan?

Life's full of them -- particularly if you live a long time. From earliest childhood most of us may recall the then-famous names and slogans of stuff like milk of magnesia, malt and Lane's emulsion. In later life we might have considered more adult stuff such as Baxter's Lung Preserver, then on to preparations that killed the meanest thirst and fed the greatest hunger and, if one lived in the US, went all the way with LBJ.

Our schools' aspirations tended to be expressed in Latin phrases such as *Facile Princeps*, even *Domine, dirige nos*, and then later in more ethnically appropriate mottos like *Kia Maia*. As life progressed we may have experienced many, many sayings and slogans ranging from child-care centres seeking to project trust and caring to psychics seeking to become new-age professionals.

If you have internet access you might like to Google a site named Sloganizer, tap out a name like polio or PPSS and be fed an endless stream of slogans including "Polio Can Do", "Building Smiles", "Innovate your World", "Firstclass PPSS", even "Polio Survivors Rock".

Property agents, supermarkets, sports clubs, towns, cities, car companies, nations even -- they've all got them, which doesn't diminish the fact that the Post Polio Support Society board would like to find a suitable motto or slogan that may brand, for example, brochures for health professionals, pamphlets and other publications.

A dictionary definition is that slogans are short phrases that are used over and over. They may be easy to remember and mostly designed to help create a favourable image of a company or a product. We in the PPSS might well be regarded as a company -- a company of survivors who do their own thing as best they can. To quote the rehabilitation treatment staff at Rotorua's QE Health, polio survivors are the most self-reliant of the many types of patients they see.

Haven't we got a slogan already?

Well, no. It's not in the rule book, which spells out the exact nature of the society and its mission to support polio survivors. Beyond that, it seeks to nurture research into post-polio syndrome, to inform members about progress in diagnosis and treatment and to develop community awareness and understanding of the Society. But in short, we need a slogan. Any suggestions? But please, not "polio rocks". We know all about that one.

-- JW



President's Message

Hello to you all. I guess the most important tradition to keep is that of condolences and we are saddened to learn that Tom Radburnd passed away on 15 March as the Christchurch group were preparing to have a day out by coach. I extend to Joan and the family our sincerest sympathy.

Get Well Greeting:

Likewise the 'get well' wishes are next to be expressed and if you fit into this group of people then this greeting is especially for you.

Polio News March 2007:

Well done to the new Editor. The updated style and clear text in March made it an immediate hit, at least with me. I look forward to the issue for which I am preparing this report.

Wellington meeting:

The Board of Management had a two-day meeting in Wellington during the first weekend in March, the second such meeting that I know of during my time on the board. Funding to make it possible was made available from the Duncan Trust through Jeannie Warnock who was at our conference dinner last September in Wellington.

We spent more the half the first day on board business, followed by a look into the crystal ball and where our future might be heading. This is a very vexed question and there do not seem to be too many immediate answers in the long-term view. By coincidence the Australian polio fraternity back as far as the Polio 2000 Conference had intended to hold a further joint conference around the year 2003/4. Finally it has been arranged for May and we will be represented in Parramatta, New South Wales, for the two day 'think tank' on May 3 and 4. I believe that we should mimic each other's plans in future years and act as sister societies where-ever and whenever possible as we have much in common in the interests of polio survivors on both sides of the Tasman.

Mary-ann Liethof Visit:

We invited Mary-ann Liethof from Melbourne to be our guest for the two-day board meeting and to help us understand the co-ordinator role she has in Victoria. She works single handedly with the exception of a part time assistant who has the flexibility that suits Mary-ann's requirements.

Their organisation receives some state funding that allows for Mary-ann's salary and expenses separate from that of the membership subscriptions that they receive. She had some very good advice to offer our management team and ideas that we are looking to implement for the benefit of the board and our members. We will keep you posted on these ideas in future issues.

Manawatu Standard report:

I received a call from a writer, Mervyn Dykes, who is a reporter for the Standard in Palmerston North, requesting information about the 50th anniversary of the Salk Vaccine in NZ. I suggested he telephone Raylee Murphy and get her to answer his questions.

This resulted in two different articles being published and it has created interest in other regions of the country in particular Nelson. I have had several calls from that area including one from an occupational therapist at the Nelson / Marlborough DHB who has been fielding enquires from survivors in the area. It is very obvious that we have not got our message out there when these new contacts phone in on the 0800 number.

Wanted: (Or looking for!)

Do you have time to spare? Like to get more involved in voluntary work for this society? Each September the PPSS members elect the Board of Management and you can seek to have your name included in the voting paper as simply as that. The executive consists of President, Vice President, Secretary, Treasurer plus not less that two or more than six Board members. Inquiries would be welcome.

Until next time take care and keep safe.

Ray Wilson, President

Futures Recommendations Discussed by PPSS Board

Six recommendations from the futures committee were discussed by the PPSS Board during the Board meetings in Wellington. Some were deferred for further consideration. Two that were approved were that demographic information about polio survivors in New Zealand be surveyed and that the PPSS produce a well-designed guide about polio survivors' special needs for members to hand to health professionals. The futures committee reported that more information about polio survivors in New Zealand -- such as the predominant degrees of disability -- was important for future planning, as was the need for doctors and others in the health field to be better informed about aspects of treatment for polio and post-polio-syndrome patients. The futures committee was formed at last year's annual general meeting and briefed to make recommendations to the board.



COLD FEET? STAY COOL: WEAR THIS!

Here's autumn already, breaking into colours and reminding many polio survivors to think about how to keep their feet warm as winter looms.

"Polio Feet" is a well-known phenomenon. According to polio guru Richard Bruno, Ph.D., the process that causes polio people's feet to turn cold and become difficult to move is the same process that caused paralysis after the original polio.

The polio virus which got into the spinal cord either destroyed or damaged the anterior horn cell motor neurons that send messages from the brain to the muscles. Another kind of motor neuron affected by the virus was the motor nerve that controls the muscle around your blood vessels. When these muscles died there were no motor nerves to tell the blood vessels to contract -- and if blood vessels can't contract blood "pools", particularly in the veins.

Here's what Dr Bruno says: "Polio feet are caused by warm blood, that should be in the centre of your body, flowing out into the hands, arms and especially the legs -- since gravity is pulling the blood down. The warm blood pools in the surface of your skin and, because the blood vessels cannot contract, the result is 'polio feet'.

"The venous pooling causes your blood to radiate heat into the environment. People who had polio keep the world warm, unfortunately at their own expense. The price of this is a thorough cooling of the limbs and all tissues of the limbs."

When heat leaves the veins the motor nerves near the surface of the skin start to cool, the muscles just below the surface start to cool, and the chill spreads muscle to muscle, muscle to bone and the muscle loses elasticity and becomes harder to move.

"When the motor nerves aren't functioning well the muscles aren't going to function well. If the muscles don't function well there is going to be muscle weakness. We think that muscle weakness and the loss of body heat are causing fatigue, and we think that people who lose their body heat into the environment are burning calories to maintain their body temperature, so there are fewer calories to keep moving."

The answers? Dress in layers. Keep warm. Thanks to our farming and outdoor recreation people there are big ranges of warm skin-layer and outer-layer clothing on the market in New Zealand. Polypropylene thermal wear comes in different weights, colours and styles, and up at the top of the range are woollen thermals popular with trampers because they tend to need washing less frequently.

The polypropylene thermals are easy to wash and quick to dry. Sports stores, department stores and farm clothing stores are places that can help you stay warm this winter.

(These comments are not to be accepted as any kind of substitute for professional medical advice).

Walking Sticks: If you're just up to that stage of disability where you need a walking stick for assistance, be sure that you get a good grippy tip for it, specially with winter coming on with slippery foot-paths and wet patches on floors. There are a lot of rounded rubber tips on the market (even from disability resource centres!) that are quite risky in slightly slippery conditions. Proper tips with deep concentric rings are available for just about all diameters of walking stick.

Stools: If you can't stand for long at the kitchen bench and you haven't got a dual-level kitchen

Tips and tricks

arrangement like Ethne and Des Crabb (photo-story last issue), a swivel-top stool can be a useful aid. They vary from bar stools with backrests to plain smooth-top stools, some adjustable for height, some not. Strategically placed, they can give you swing-around access to sink and side bench, side bench and cooking top. Before you buy one, just make sure the seat is securely fastened to the rotating bit on which it sits.

Talk about it: One of the great things about PP support meetings

is that many good ideas come not just from guest speakers but also out of talking with each other over a cup of tea. Overheard recently:

- People who have falls commenting that they're always on the lookout for sharp and dangerous objects in the immediate vicinity.
- A user of elbow crutches who has padded the handgrips with velcro-backed sheepskin.
- Calliper-wearers know it's best to keep the knee-joints lubricated and covered with leather to keep grit out and also protect clothes.
- If you're visiting and maybe out of your comfort zone, don't lean for support on a tea trolley.





Members of the PPSS Board meeting in Wellington in March. From left Susan Kerr (Picton), Jim Webber (Polio News), Jenny Green (Dunedin), JB Munro (Secretary, Dunedin), Des Crabb (Paengaroa), Claudia Mushin (Wellington), Ray Wilson (President, Oamaru), Philippa McDonald (Vice-president, Wellington).

Photo: Mary-ann Liethof.

Information, social contacts motivate support groups

Mixing information and social get-togethers is a successful formula for polio support groups. This was one of the messages brought to New Zealand by Mary-ann Liethof who spoke to the PPSS Board in Wellington in March.

She described how, in her state of Victoria, getting information out to polio survivors was a major effort: "Information sessions are the key to helping the support groups. New people want information more than the social contact. The most successful groups I have combine features -- speakers, tea, chat -- and they just keep on keeping on."

Mary-ann said much of her job involved attitudes to polio. Although Paraquad -- the overall disability organisation in Victoria -- provided free psychological services few people took advantage of them: "They find their own way of coping. Some people still have the 'got to fight it' attitude. When I go out I say to them 'that's not going to keep you mobile!'"

Victoria has a polio network similar to New Zealand's -- but it's bigger. Victoria's population is 4.5 million and there were 6792 notified cases of polio during the 1930-1964 years.

In New Zealand there were some 10,000 cases from 1915 to 1961. There are 20 support groups throughout the state and 1600 people on the polio database receive free newsletters. However the funding setup is vastly different across the Tasman. The Victoria polio network is a service of Paraquad Victoria and is funded by the state's Department of Human Services to the tune of \$A84,300 a year. Mary-ann Liethof is the paid fulltime community officer and gets \$A50,000 a year, a car, running costs and cellphone. She is assisted by a part-time voluntary administration worker and Paraquad Victoria provides \$A10,000 towards overhead expenses.

The polio network has an elected advisory committee of eight who serve for up to three years. They meet monthly in Melbourne and receive lunch and travel expenses. Minutes of their meetings and also the organisation's charter and terms of reference are all posted on the network's website (www.polionetworkvic.asn.au). Some of the 20 support groups, all of which are overseen by Mary-ann, are separately incorporated with their own boards -- again a good comparison with New Zealand where the bigger support groups also have their own incorporated societies.



Medical matters

PROBLEMS EATING? MAYBE POLIO TO BLAME

Some polio survivors in New Zealand are experiencing difficulties at times swallowing comfortably -- which can baffle some doctors as there might be no apparent cause for it.

Once again, according to Dr Richard Bruno, there could well be a polio-related issue:

"The difficulty is usually high in the throat, not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own secretions.

"Polio survivors also have swallowing problems below the throat. The muscles of the throat and oesophagus should contract in a co-ordinated sequence, like a snake's muscles move, to inch food downward and into the stomach.

"Food gets stuck when the oesophagus doesn't contract and its muscles go into spasm, not unlike back muscles going into spasm when your leg muscles are too weak to hold you up. Food usually gets stuck right behind the top of the breast bone. When it does, it's painful and scary. Even if food makes it down to the bottom of the oesophagus, in some polio survivors the 'valve' just above the stomach doesn't open, prevent

ing food from entering, a condition called achalasia." An early polio researcher, Dr David Bodian, discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When this damage was severe and breathing control neurons stopped working Bulbar polio was diagnosed. However the most common bulbar polio symptom was trouble swallowing, not trouble breathing, because the polio virus also damaged the bulbar neurons that control the vagus nerve which activates and co-ordinates muscles from the throat to the stomach.

Dr Bruno says that a low dose of muscle relaxants, taken 30 minutes before eating, can relax the oesophagus and allow food to slide down more easily. And in the case of polio survivors who have a chronic sore throat, husky voice or burning sensation in the chest, they should be assessed for reflux by an ENT doctor who will look at the upper throat and vocal chords, and another specialist who may do a gastroscopy (with light anaesthesia) to look down the oesophagus and into the stomach.

(These comments are not to be accepted as any kind of substitute for professional medical advice).

History is Populated with High-achieving Polio survivors

If you've ever doubted that polio survivors often do unusually well in their lifetimes, consider the number of really famous folk who had polio.

Although Pharaoh Siptah, who lived 20 years until 1193BC, and Roman emperor Claudius (10BC to 54AD) are regarded as being among the first likely cases of polio, the earliest recorded polio survivor was Sir Walter Scott (1771-1832). Hit by a fever, then by the loss of right leg power while just a toddler, he survived to become a sturdy youth and a great writer.

Others on the list of notable polio survivors: Actor Lionel Barrymore (1878-1954), Franklin Delano Roosevelt (1882-1945), chocolate company founder Frank Mars (1883-1933), Australian marathon swimmer and actress Annette Kellerman (1886-1975), Olympic track and field star Ray Ewry (1873-1937) and noted German teddy-bear seamstress Margarete Steiff (1847-1909).

More from the hall of fame: Actor Alan Alda, boxer Julius Bort, sci-fi author Arthur Clarke, Olympic diver George Coleman, singer Judy Collins, film director Francis Ford Coppola, actress Marion Davies, British rock star Ian Dury, actress Mia Farrow, actor Mel Ferrer, opera singer Marjorie Lawrence, actress Ida Lupino, singer Joni Mitchell, golfer Jack Nicklaus, physicist J Robert Oppenheimer, singer Ray Peterson and famous violinist Itzhak Perlman.

Dinah Shore (1916-1994) was another of the many entertainers who survived polio, also Lord Snowden (photographer and Princess Margaret's former husband), Harley Davidson genius Brooks Stevens, Canadian actor Donald Sutherland, Italian opera singer Renata Tebaldi, and Neil Young, rock singer in the 1970s and 1980s.



News from PPSS NZ

Support Groups

98th BIRTHDAY

Lower Hutt had an excellent afternoon meeting to celebrate the 98th birthday of the group's oldest member, Frances Sykes. Also present were President Ray Wilson, who had been attending the PPSS board meeting in March, and vice-president Phillipa McDonald. Frances Sykes is a champion knitter and her goal at present is to make 98 teddy bears this year - she has knitted well over half already! The Hutt group was also sad to acknowledge the death of Carol Rowse, one of its members and a past PPSS president.

ALFRESCO LUNCH

Members of the **Waikato Branch** met early in March for the usual New Year get-together, a pooled lunch alfresco style at the Coes' house where the lawn near the house is flanked by shrubs and trees. Two tarpaulins were slung between trees and the house to provide welcome shade over a large area and the tables of food and drink were handy to the seating. The shading and shrubs helped to temper the warmth of the day. It was an easy, relaxed event, conversation flowed easily, revealing a lot of shared experiences (we seem to hear something new each time).

Maurie Holyoake gave us a demonstration of his new "collapsible runabout" scooter. In a few minutes the four pieces in his car boot were assembled without a spanner, and he was scooting around on the lawn showing its manoeuvrability and excellent lock for a 4-wheeler. It bears the name "Walk on Wheels" (see story this issue). Maurie has this little scooter in addition to his regular more robust mobility scooter which takes him down to the shopping centre.

After the meal we discussed ideas for the year ahead and whether to vary our seasonal routines. The general response was to continue to keep it simple, affordable and occasional. Our next gathering is expected to be mid-winter at Edith's, with a speaker and topic still to be confirmed.

Jean Coe, joint coordinator

PRE-FUNERAL NEEDS

North Otago started the year late as members were involved and busy with other projects, so the February meeting was held over till March. We invited one of the local funeral directors to come and talk to members about being prepared and knowing what details are needed when one has the task of contacting the funeral home. In our area we have two choices of

who to invite, however we chose a young man who a few of our members had met before. It is a topic sometimes put aside, but knowing what we need to have at our finger tips when the time comes can make a difficult and stressful time a little less stressful.

Many questions were asked, including whether we need a birth certificate of the person who has died, and what details we need to know about the deceased's parents and so on. It was a very informal discussion. We had lots of laughs and in fact a jolly good time was had by all -- including afternoon tea.

We don't have a planned roster of meetings for the year. We go with the flow and usually find something of interest to entice our members out. Our numbers are dropping which is a concern as it means that our ageing members are either not up to coming or are in hospital, or are no longer with us. It was jokingly said at our last meeting, when we were discussing the growth of polio in countries that was reported on the front page of **Polio News**, that only an epidemic would keep our membership numbers up! Of course everyone knew we were joking.

We plan to meet again on either the first or second Saturday in May at the CCS Waitaki rooms, 316 Thames Highway, Oamaru at 2 pm. -- Trish Hill

FIELD OFFICERS CHANGE

Sad news / glad news from **Western Bay of Plenty**, where Gill Raine, field officer for the last four years, has resigned. On the glad side Deirdre Redmayne has joined with the group. She has worked in allied health fields and comes with Gill's recommendation. First get-together for the year is lunch at the Kaimai Cafe, close to the McLaren Falls

NEW MEMBERS WELCOMED

In **Kapiti** new support group convenors Peter East and Bill Choat welcomed new members to the group in March, when they viewed the Australian DVD about support services in Victoria. They enjoyed afternoon tea at the Easts' home in Raumati and in spite of three people absent due to "bad day" syndrome everyone enjoyed the meeting. Self-confessed computer nerd Peter East produced the support group's first newsletter in April to gauge feedback and future planning and to provide a list of useful websites for people with internet access. The group has a local contact list of 13, not counting the PPSS members from further north who also attend Kapiti gatherings.



More news from PPSS Support Groups

WELLINGTON REVIVAL

Claudia Mushin, who resigned from the PPSS board recently for health and work reasons, and PPSS vice-president Philippa McDonald are reviving a support group in **Wellington**. They have built up a contacts list and are planning the first group gathering in May.

MID-NORTH ANNUAL

Secretary Ruth Inglis gave group and national news at the annual mid-north meeting at **Kerikeri** where four members from **Whangarei** joined locals for lunch and exchanges of views, ideas and problems in the medical field. Jan Miller of the Alzheimers' Society spoke at the April meeting of **Northland** group at Bas Sutcliffe's home.

MEMBERSHIP GAINS -- AND LOSSES

With the arrival of warmer weather, **Christchurch** members have been out and about and showing that, although we are getting older, we are still full of go. We are also pleased to be joined by the occasional new member even at this late stage in our group. It would be interesting to know if groups elsewhere in New Zealand are also experiencing these additions to membership.

Not that overall numbers are increasing as, sadly, we continue to lose valued members as the years creep up. Notable recent bereavements include Tom Radburn, George Margetts and Ivan Wadley.

We continue to make good use of the wheelchair bus for outings, having made a day trip recently to a Co-optown farm displaying a variety of animals, coupled with a lunch stop on the hills overlooking Akaroa. Two more bus trips are planned for later this year. Our monthly meetings continue to be lively affairs, thanks to our committee finding a variety of entertaining and informative speakers and thanks also to the friendly exchanges among those who attend.

-- George Ross.

TRAVELLERS' TALES -- AND HELLO ARTHRITIS

I hope everyone has kept well since the last news bulletin from **Eastern Bay of Plenty**. At our monthly support group meetings we've had guest speakers who told us about their travels to Cambodia fundraising for Oxfam and biking through Thailand.

At our last meeting we had a guest speaker from the local social arthritis club and apart from her very entertaining talk it was amazing how many similarities

there are between people with arthritis and people with polio, namely the need to rest and to preserve energy and on the other hand to keep exercising.

Also sounding very familiar is their quest to retain access to Queen Elizabeth Hospital as it is the only hospital in the southern hemisphere specialising in arthritic conditions.

Several of our members have attended the Falls Prevention Programme which was recommended at the last PPSS Conference and have benefited from it.

All our members received an issue of the "Family Care" magazine, which is full of practical help for family carers and includes an excellent article from Christopher Wornall who in 1980 contracted acute poliomyelitis in the foothills of the Himalayas.

Gisela Sonntag, Field Officer

MID-YEAR DINNER, BRIGHTWATER

Hi, everyone, from **Nelson-Tasman District**. Jenny and Paul are away having a well-earned holiday, so I'm filling in for this month's newsletter report. Anne and I are just back from a holiday down south which was very enjoyable. No-one has been in touch since we arrived home apart from Ian Frost, who is having a few problems. We all hope you improve soon, Ian, and seek help when you need it -- which applies to everyone.

Our mid-year dinner will be held at the Brightwater hotel on Saturday, June 23, at 12.30 -- please advise Jenny Kissane (545 1030) or me (547 7043) by June 18 if you're able to join us.

Rex Wastney.

NEW-COMPUTER MISSION

Taranaki support group is looking to replace its tired computer with a new one, so it is seeking a grant and also, from Microsoft Community Donations, some new software. Shirley and Tony Hazlewood are both on the Taranaki committee of the DPA and they welcome the signing by New Zealand of the new United Nations convention on Disability. Says Tony: "It now means that the Government has to follow the NZ Disability Strategy. Disability is now a human rights issue, not a social one."

Deadline for August issue: 15 July

Editor Polio News: Jim Webber,

103 Amohia Street, Paraparaumu 5032.

email ferris.webber@paradise.net.nz



News in Brief

'Good Listener' heads Polio Network



Mary-ann Liethof, guest speaker at the March PPSS Board meeting in Wellington, once lived in Christchurch. Now 47, she lives in Melbourne's eastern suburbs with her retired partner. She had no experience of polio till she became community officer with the Polio Network in Victoria three years ago. However she consulted widely and having worked in the community sector for 18 years was "a good listener". Mary-ann co-ordinates Victoria's 20 support groups, facilitates information sessions, edits a quarterly magazine, provides general information to people who have had polio and she believes that polio survivors' networks benefit greatly when they are assisted by paid co-ordinators

PRESIDENT, BOARD MEMBERS AT SYDNEY CONFERENCE

President Ray Wilson of Oamaru and vice-president Philippa McDonald of Wellington are attending the "Polio Australasia -- Designing a Future" conference in Sydney early this month.

They will be supported by board members Susan Kerr of Picton and Jenny Green of Dunedin and board secretary JB Munro, also of Dunedin.

The think tank on the future of polio networks on both sides of the Tasman will include polio network representatives from all states of Australia and specialists from polio services.

The event has been organised by the Post-Polio Network of New South Wales with a view to formulating strategies to ensure the continued operation of post-polio networks in New Zealand and Australia.

Disability Bills Approved

Two bills affecting disabled people and employment have been passed with the support of all parties except National and ACT. They are the Disabled Persons Employment Promotion (Repeal and Related Matters) Bill, which replaces the DPEP Act 1960, and the Minimum Wage Amendment Bill. Council of Trade Unions secretary Carol Beaumont says the old law was discriminatory: "It reflected attitudes towards disability which are unacceptable."

New D.I.S. home

The Wellington-based Disability Information Service has moved to new premises in Petone. It is now operating at Shop 6, 5 Britannia Street. There is parking at the door.

Polio people in the news

Hokitika polio survivor Patsy Bell was one of several PPSS members featuring in news media recently. A notable community service worker on the West Coast, she marked the 60th anniversary of her life with polio in April. Patsy had polio in 1947 at the age of seven and has lived with lower body paralysis ever since.

Disability, she says, is merely a state of mind: "You are only ever as disabled as you want to be." The only West Coaster to get polio in 1947, she went on to excel at school, work in a delicatessen and become a CCS committee member.

Patsy married in 1963, had two children and now has six grandchildren. She won a Hokitika Rotary community service award in 2005.

Pakistan Polio spike

A sharp jump in polio cases in Pakistan has been attributed to parents in northern Pakistan refusing to allow their children to be vaccinated -- mostly because of rumours that the vaccine was an American plot to sterilise Muslim children.

Polio in Pakistan is reported to be concentrated in the northwest frontier province where 60 percent of vaccine refusals were said to be for "religious reasons". Some 24,000 children were not vaccinated and World Health Organisation officials said there could be a fresh opportunity for the virus to spread.

Insurance caution

If you have any mobility equipment attached to your vehicle, make sure it's covered by your insurer.

Lois Campbell of Wanganui had a problem following an accident with her car recently -- her rooftop wheelchair hoist wasn't covered, leaving her with a \$4500 bill for a replacement, plus a trip to Palmerston North to a registered fitter:

"Tell your insurer if you have any aids fitted to your car, otherwise they might not be covered."



MY ELUSIVE KAFO DREAM

You wouldn't think it would be the stuff of dreams -- a calliper, a brace, a KAFO, call it what you will. It became a dream because I called my old calliper many other, mostly uncomplimentary, names. On a good day it was just "the leg". But when it caused pain, when it failed mechanically as it did often, it was in deep trouble. So came the dream, a long-running dream, of having a proper, comfortable, well-made calliper.

I'm fairly easy on callipers. Not overweight, not careless. I don't get sand near it. I buy good shoes that fit around it quite well. Any calliper, to my mind, should last many years. Given that it is properly made. Mine was not.

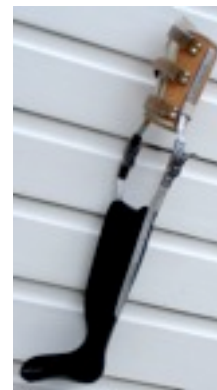
The knee joints were too low. The metal brace across the upper leg bits was too high. The orthotics providers fixed that by moving it down a bit. Sometimes I fell. Sometimes the joints wouldn't lock. Once they jammed so tightly (I was getting into my car) that I had to take it off before driving away.

I grizzled so much that Orthotic Centre agreed, round about April 2005, to do a new one. Great, I thought. That would allow Leg 1 to be fixed. Good news, at the time. I was measured for it in June. A casting session followed in October. I wrote complaining about the delay. Orthotics replied in December citing staff shortages. What I hadn't realised that because I already had a calliper, albeit a bit on the shonky side, I had slipped to Category D. There followed an amazing schedule. A fitting in Wellington in January '06, another in April, three in Paraparaumu in May, another one that slipped the orthotist's diary. July, August, more fittings.

Remember we're talking about two bits of alloy, two hinge fittings, a plastic lower leg piece that goes inside a shoe, a brace across the back, support straps and a leather cuff for the thigh. Not a huge task, one might think. By comparison it takes about three weeks to measure up a big trailer boat, stitch together a new trailer with heaps of little support wheels, have a final size and winch fit and splash, it's finished. Galvanised. Warranted. Registered for the road.

The orthotist in Wellington said the Auckland workshop wasn't doing what she had requested. Seemed to have their own agenda, she said. Mis-fitting bits came back. Was it because I'd written the letter? But in October '06 things were looking up. Then at yet another "final fitting" Leg 2 arrived with some iffy riveting. The lower leg moulding had split beside a rivet. Another piece had to be cast. Another fitting in November. Then another "final" in Paraparaumu. It was looking good.

Then the orthotist told me she'd quit. But all was not lost. One more fitting in Wellington. I stood in Leg 2,



self supporting. Not uncomfortable. A couple of minor tweaks -- it was almost done. On her last day there was a call to say it would be ready on Monday, delivered to Paraparaumu's Health Centre. And so it was, after twelve orthotic sessions, eight hours' travelling. . .but I was glad to get it. It looked good. Some little things still to rectify but it felt good.

I can't imagine the cost. My job file envelope at Orthotic Centre was swelling like a huge wallet during this journey. I bet the dream cost more than a boat trailer. -- JW

(Footnote: The basis for this story is the subject of a complaint to Capital and Coast D.H.B.)

Electronic calliper responds to weight-bearing signals

A new version of the "E-Knee", an electronic stance control calliper, locks and unlocks the knee mechanism at any degree, depending on various conditions.

The E-Knee uses a microprocessor that responds to weight-bearing signals from a patient's foot or shoe -- it locks on ground contact and unlocks the calliper's knee joint when the foot sensor signals loss of weight, allowing the leg to flex as it moves forward.

The development overcomes the problem of KAFO (knee-ankle-foot orthosis) callipers clicking into straight-legged mode for walking and having to be unlocked so that the wearers can sit down.

An Australian old-polio wearer of an E-Knee was fitted with his new KAFO 18 months ago. He had been suffering from progressive muscle weakness in one leg, pain in the opposite hip, deteriorating gait and regular falls. He can now walk over rough ground and negotiate stairs without difficulty. His E-Knee calliper cost \$A8500 and he was assisted by his Lions Club to purchase it.

Clever Wheelchair Loader



Above, the loader lifts a wheelchair out of a wagon and delivers it to the driver's door. The process is reversed to return the chair.

A Christchurch company has developed a wheelchair loader that lifts a regular folding wheelchair out of the back of a vehicle and delivers it to the driver's door. A Russian engineer in Christchurch had the original concept. The latest development of it is subject to patent rights.

The EZloader competes with the familiar roof-mounted wheelchair carriers but keeps the wheelchair under cover. The loader is designed for a wide variety of wagons and people movers ranging from a Suzuki Wagon R to vehicles like the Holden Astra, Ford Mondeo, Nissan Prairie and Kia Carnival. In a straightforward fitting the loader costs around \$6500 plus GST.

"There are vehicles that we haven't yet seen and assessed," says Ernie James, spokesman for the makers. "A quick guide to suitability is having an opening tailgate and reasonably level entry."

Folded across inside a vehicle, a wheelchair in place takes up 450 to 500mm with the rest clear for normal carrying purposes. The device is powered from the vehicle's electrical system and operated from the driver's seat. It requires only the normal amount of operating space in a standard wheelchair park.

Something Old Something New



This unusual powerchair made by Ikon Engineering in Auckland from 1992 to 1996 never made the mainstream market in spite of having an innovative design and being comparatively cheap to make. Reason: It was too smart. Ikon manager Dave Giles says they were ahead of their

time but funding agencies didn't go for them. Like other powerchairs they use 12V batteries and joystick control. They sell on the secondhand market.

This HS295 folding scooter is one of the new models from an Auckland-based disability-equipment franchise, Walk on Wheels. The venture is expanding throughout New Zealand with a massive range of disability and mobility products. Company owner Tony Robinson says the \$2500 scooter is selling as a shopping model that can also fit in a car. A larger, \$3700 model is the company most popular seller as a "car replacement" alternative.



Did you hear the story about the variously disabled folk who turned up at a self-defence class? Ethne Crabb, now mostly in a wheelchair, recalls the day when . . .

A Pinch and a Punch . . . or Knees, Keys to the Rescue

"Self-defence for the Disabled" the brochure said and I thought "Why not?" So away I went, 10am to 3pm, bring lunch, okay. There were quite a few of us and two who I knew. We had three bionic knees, two bionic hips, arthritis, rheumatoid arthritis, IHC -- and polio. All of us very different. Our tutor wished to know how each one of us was affected by our disability and what our body strengths were.

We learned how to yell at an intruder and not worry much about the language we used. Being a lady does not come into it. We have to turn into a screaming, raging ball of hell fire. More often than not the aggressor will not be expecting anything more than passive resistance.

We were taught how to use legs, feet, elbows, hands, teeth. How to fold our fingers and thumbs correctly so as not to break them when all we really wanted to do was break him somewhere. We now know the right way to pinch someone. Simple, boy. And it hurts, a pinch in the right place. If we are not so good on balance, lean on the aggressor -- he won't be expecting it -- and that will give us support enough to get nasty and mean.

Break his nose with an elbow, get his eyes with fingers, grab a handful of you-know-what and give them a twist. Roll knuckles on back of hand, ouch! Hurts!

Scrape heel of shoe down shins. We don't wish to feel sorry for him. We were shown the correct way to kick so we hurt an aggressor and not ourselves -- very easy to break one's own toes and that's not the idea at all. Do him a mischief, that's the idea. Surprising how high one can lift one's knee if one has to. And those car and house keys -- they're lethal weapons.

We were shown how to roll a fella off if he was on top of us. If we were approached from front or behind and held around the throat we found out how easy it is to break his little fingers and thumbs.

Some of us with walking sticks were given good tuition on using them. I wouldn't like to mess around with one of us after this course. It all sounds nasty but who the hell wants to be got at? It is very wise to know a few tricks. They do give one some degree of confidence. After all, whoever it is that attacks us has no feeling whatsoever if we get hurt in the process.

I can't understand why more women don't take these self-defence courses. The old saying "it will not happen to me" is so far out of date these days, it's useless. I only used a walking stick when I did this course. Now that I'm in a wheelchair I really need an update. The other problem is that Des has never let me practise on him, so it's never been put to the test.

The Global Polio Eradication Initiative is being bolstered as contributing nations weigh in with seemingly massive amounts of funding.

New contributions listed by the World Health Organisation and its affiliates include \$430,000 from Australia for oral polio vaccination in Nepal, \$4.4 million from Canada for Afghanistan, \$10,000 from Denmark for Niger, and \$1.2 million in global funds from Germany. Tiny Luxembourg has donated \$2.76 million for global funds and leads donor nations on a per capita basis.

Massive funding Pours into GPEI Programmes

Other contributions include Iceland \$50,000, Ireland \$10.4 million, Japan \$8.9 million and Monaco \$30,000.

Rotary International has given \$4.6 million, the Russian Federation has contributed \$10 million to augment global funds between 2006 and 2008, the United Nations Foundation has

contributed \$3.4 million and UNICEF national and regular resources have provided \$12.9 million for priority countries. \$300,000 from USAID is earmarked for north Sudan and the World Bank has contributed \$6 million for oral polio vaccination in Afghanistan.

Long-time polio eradication advocate Alan Court, who heads UNICEF's programme division in New York, says that achieving a polio-free world would mean that "no child will ever again be paralysed by this terrible disease."

(Note: US dollar totals shown)

Kiwi Kids Missing Out on Vaccine Jabs

One in four New Zealand children is not fully immunised before age two.

The recently released National Childhood Immunisation Coverage Survey claims that only about 77 per cent of children get all the recommended immunisations before the age of two – significantly lower than almost all other Western nations.

The vaccines involved in the survey immunised against poliomyelitis, hepatitis B, meningococcal disease, diphtheria and whooping cough. Health Ministry public health medicine senior adviser Dr Alison Roberts said the aim was to have over 95 per cent of children aged under two immunised.

The most common reasons people chose not to immunise children were perceived health risks from vaccinations, using alternatives to vaccinations to guard against disease or getting vaccinations overseas, Roberts said.

Two Lifetimes in "the Lung"

Two women have survived virtually a lifetime of polio in iron lungs. One, June Middleton of Melbourne, who has relied on an iron lung to stay alive since contracting polio in April 1949, received a Guinness World Record certificate to mark the marathon.

June, 81 this month, was one of about 70,000 Australians affected by polio over 30 years. She spends about 16 hours a day on the NPR (negative pressure respirator).

Her achievement prompted an American editor, Larry Kohout, to report the survival journey of Martha Mason of North Carolina, who went into an iron lung in September 1948 when she contracted polio. She spends virtually 24 hours a day in it. She wrote a book, "Life in the Rhythm of an Iron Lung", about it.

FOCUS ON THE "HOT FOUR" IN WORLD POLIO WIPEOUT

Global polio eradication is focused on four countries -- Nigeria, India, Afghanistan and Pakistan -- and experts now believe that the end of the disease is in sight. They are using potent new tools to work towards wiping out endemic polio, including fast-acting vaccines and new laboratory processes that halve the time needed to detect the poliovirus.

"The global eradication of wild poliovirus is technically and operationally feasible," says Dr Steve Cochi, chairman of the technical oversight body of the Global Polio Eradication Initiative.

There is caution mixed with confidence because polio has shown its ability to travel great distances by air or sea, and countries are being urged to do more to protect themselves from re-infection. Warnings have also been issued that full immunisation of all travellers from any polio-infected area may be needed under international health regulations.

The new quick-acting vaccine, known as mOPV1 (monovalent Oral Polio Vaccine) is reported to have protected 30 percent of susceptible children in northern India, compared with 11 percent for the standard "trivalent" vaccine.

Polio "stubbornly persists" in Uttar Pradesh where 250,000 children born every month need vaccination.

Carer's Card Programme Expands

The Australian "Companion Card" concept is being picked up by other states following its startup in 2003 in Victoria, where the state government is keen to support other states in adopting the scheme. The card is issued to people who have life-long disabilities and require attendant care support. It provides "two for one" access to events and venues where there is a need for a carer to accompany the disabled person and where the scheme is recognised by organisers.

Lime Line for Accessible cabs

Disability-conscious Sydney businessmen have set up a premium wheelchair-accessible taxi fleet that charges normal industry rates -- \$A2.90 at flagfall and \$A1.68 a kilometre in urban Sydney. The venture is a wholly-owned subsidiary of Macquarie Bank and some of the profits go to support disability charities. The company plans to expand into all Australian state capitals. Its website is www.limetaxis.com.au and, if you're visiting Sydney, the number is 13 LIME.



Photo: Murray Wilson, Manawatu Standard.

Moving story stirs Post-polio response

Manawatu journalist Mervyn Dykes has written a feature about post-polio syndrome that has moved several people to call the PPSS free-phone number for information about what he says is "like a horror movie where the villain seems to have been killed".

Himself a late-1940s polio survivor, Mervyn Dykes went on to become an active multi-sportsman and journalist. He interviewed PPSS support group leader Raylee Murphy (*pictured, left*) for his feature story in the Manawatu Standard and other newspapers. It describes how some 800 New Zealanders live with the prospect of being revisited by past polio, among a global population of polio survivors who in the 1970s began to suffer from tiredness and weakening muscles.

Raylee Murphy, 66, contracted polio at age seven. Today, like many post-polio syndrome sufferers, she uses mobility aids when she needs to and urges polio survivors to conserve their strength to preserve it. She still leads a busy life but feels the frustration of not recovering so quickly from "pushing herself".

The feature story outlined the latest theories about causes of the loss of energy experienced by most people with post-polio syndrome. As one Palmerston North doctor, aware of polio issues, put it: "You've still got polio. Your body hasn't beaten it but merely subdued it. If your immune system should weaken, it will come back".

Mobility-equipment Wagon

The late Denis Hogan's 1985 Bluebird Nissan stationwagon is for sale. It is equipped for a disabled driver requiring hand controls and has a wheelchair hoist to the roof. The vehicle's current mileage is 97,159 and it travels very nicely. Enquiries to Mrs Helen Hogan Phone 03 338 9552.

Deadline for August issue: 15 July

**Editor Polio News: Jim Webber,
103 Amohia Street, Paraparaumu 5032.
email ferris.webber@paradise.net.nz**

Hamilton is A-Okay for Accessibility

Disability radio host Edith Morris pre-recorded her "Talking Up Disability" programmes last month for a few weeks up till mid-April while she enjoyed an extended South Island tour.

Two frowns among the southern smiles: A flight of stairs above the mobility car parks, leading to the Kaiapoi information centre, and a parking warden's assurance that there was no disability parking at the big museum in Dunedin. Says Edith: "Overall I think our Hamilton situation is very good."