



# Polio News

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

## 2007 CONFERENCE OF INTEREST & RENEWAL

**Attendances at the 2007 PPSS AGM and Conference were down on expectations, but those who went enjoyed a forward-looking gathering of interest and renewal.**

There were more members present from the northern part of New Zealand than usual. Dr Stephen de Graaff's addresses were received with acclaim, and at the AGM members voted for a board of six people who now include two new members from Hamilton and one from Whakatane, augmenting the board which has been down on strength since the resignations of Cormac Brennan (Rotorua) and Claudia Mushini (Wellington) during the past year.

Ray Wilson, who has been president since succeeding the late Denis Hogan at the AGM in Auckland in 1998, has been re-elected -- but he gave notice that he would step down in 2008.

Nearly 50 people sat down for the conference dinner at the Novotel Tainui Hotel and several more attended for the health professionals sessions on day one and for the de Graaff presentations next day.

Dinner speakers included Hamilton orthotist Colin Storey, who delivered some amusing revelations about polio patients. Professor Tim Brown of Palmerston North -- a polio survivor from Yorkshire who was one of five New Zealanders among thousands of runners who carried the Olympic flame from Rome to the Winter Games in Turin in 2006, also spoke.

The new PPSS board met for the first time on day three while Dr de Graaff, who is Director of Polio Services and senior rehab physician at Epworth Healthcare in Victoria, had a series of discussions with individual members.

Dr de Graaff presented four addresses on various aspects of polio -- post polio sequelae, medications for polio survivors, necessary services for polio survivors and pain management

## Campaign Slogan

**WE'RE  
STILL  
HERE**

Post-Polio Health International adopted this rallying call last month to remind many countries that polio survivors still exist -- living integrated lives, actively participating in community affairs.

America mounted a major campaign involving public awareness and multi-media programmes -- even special T-shirts and community events with special speakers. There were also large-scale events and campaigns in Australia, with a big event in Melbourne that focused on disability services and a presentation by Dr Stephen de Graaff on "The Polio Brain -- or What Was I Saying?". In New Zealand PPSS board members arranged media publicity to mark the month.

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# 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 (www.) address is [nzordgroups.org.nz/postpolio](http://nzordgroups.org.nz/postpolio). and the mail address is: Post Polio Support Society NZ (Inc), PO Box 249, Oamaru.

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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, 04 905 4148, email: [ferris.webber@paradise.net.nz](mailto: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.

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# Editorial

Now here's an odd thing: Are you happy to flash your Grey Power membership card when paying for goods or services? Of course you are. There's money at stake here. That's why we sometimes prefer one shop to another. For most of us, it's a time when we don't mind being older. Sometimes we feel good when told "Well, you don't look that age".

It's not that easy when we're younger. Youthful, we can't wait to be older, more adult, apparently mature, more sophisticated. Ageing, we get to a stage where we might want to be seen as younger, far from "past it". Then once we're into the senior citizens syndrome, most of us are into it heart and soul. Get a haircut without taking the discount? Pay full ticket price at Te Papa? Not go to the movies on "seniors day". Full price on the trains? Yeah right.

So if we become disabled, why do most of us fight the inevitable? Time to say hello Dr de Graaff. The noted polio medico says those of us disabled by polio should grasp what's available as soon as we can and not wait till we desperately need it -- when it might be too late to really handle well the insidious depletions of Post Polio Syndrome.

When I hit the supermarket aisles, for the first time ever, in a wheelchair an old woman I once knew said loftily "So you're not too proud to use a wheelchair?" The question kind of floored me, but not for long. What kind of pride is there in little or no mobility, in not using a stick or a crutch, a calliper or a frame or a chair on wheels when you need it?

There is a curious aspect of public perception at work here. If you're on crutches people who don't know you might say "hey, what happened, will you be on those for long?" If you're in a chair the word is "hey that's really terrible". Disability, like beauty, is measured in an emotional sense in the eye of the beholder.

On the ground the real-world reality is what the experts tell us. Accept their assurance that it will only get worse. But please don't expect everything to go well in your search for rehab help. Probably you will encounter doctors who know nothing at all about polio. You'll almost certainly find physios whose creed is "use it or lose it", and meet OTs who are so challenged in the Arthur or Martha department that they won't help unless you're falling-on-the-floor disabled and damaged for lack of a walker or a wheelchair.

Keep the kaupapa. Get onto it as early as you can. And lean on your PPSS leaders when you're badly served by the agencies of health and disability -- some of whom post, pompous grand-sounding mission statements. Then sometimes find that they can't actually achieve them.

-- JW

# President's Message

**Hello all, and yes, "We're Still Here": This is the cry voiced and written in many countries this October to let people know that we polio survivors are still here.**

I guess, as I count down the months to my retirement from this office, my most difficult task will be sorting through the mass of papers and magazines that have accumulated at my address over the past 14 years of Board involvement. As I sit and write this message I think of all those 'Polios' I have met along the length and breadth of this land and how warmly I have been welcomed and accepted in this role.

To those who have provided me with direct links to their groups via a newsletter or news sheet I thank you. May I also at this time express to the total membership my thanks for your continued support of your Society through your annual subscriptions. As time elapses and numbers decline it becomes harder to service the needs of those who remain on the list. Please hang in there and help each other. The other item that needs to be reported is the amount of additional money paid by members as voluntary donations. No matter how much is included, requesting 50% of those donations for local expenses can reward each local group.

With the AGM now behind us I welcome new members to the Board of Management and also I pay tribute to those who have retired during the past year.

We currently await the result of our applications for Lottery and McKenzie grants. These will dictate to some degree our future planning and expenditure. It will be around mid-December before we know our future total funding.

What an asset it would be to have a person of Stephen de Graaff's calibre within New Zealand. His down to earth approach and willingness to talk about poliomyelitis makes him probably the best representative we have had to speak with us. We have gained immensely from his being available to us during his holiday time in NZ without cost for his overseas travel. His presentations were videoed by Noel Morris of Hamilton and details of their availability on disc are printed elsewhere in **Polio News**. I believe each group should have access to a set. The cost of \$80.00 per set it may be difficult for some groups, and perhaps this is a target that the board should consider.

We are, subject to finance, preparing a new brochure for the information of the medical fraternity in New Zealand. It was developed in the main by Dr Liz Falkner and covers the needs of those seeking medical help with post polio syndrome.

Some of the required funding has been sought from the Stella Anderson bequest, following a letter I submitted to the Otago and North Otago groups who have discretion as to the spending of that fund. Thank you to these two groups for your support of this project. It is interesting to remember that \$1450 was released in 1996 toward the printing of Jean Ross's "Some Aspects of Polio in New Zealand" booklet, being the only other major spending that has been achieved.

However I do not believe that this funding should be mainly used in this way, as the bequest was specific enough in the terms of Stella's will.

With the Christmas season fast approaching, may I wish one and all Season's Greetings and plenty of happy times with family, friends and those you love and care for.

**Ray Wilson, President**



## Successful Disability Expo

The Hamilton Disability Expo took place at the end of PPSS Conference week and several conference delegates visited the show at Claudelands. The Waikato PPSS support society presented a well-designed stand (left), however the usual number of displays was down to 61, from 71 last year, as some of the usual participating groups were involved away from Hamilton. Visitors were estimated at 2000 to 3000. They saw special events and a wide range of health and disability aids and services on display. The event is now in its fourth year.

# Global view

By Susan Kerr



This has been a quiet time for IPPSO (International Post Polio Support Organization). Since the Miami conference Barbara Gratzke, vice president, has been celebrating her husband's retirement with both of them travelling around the United States in their wheelchair accessible motor home. They will be back home in Florida in December. She has kept in touch via the Internet when she was able and has been meeting with PPS groups and leaders as she travels.

Harald, the president from Norway, has been ill for about a year now and Shari Fiksdal, the other vice president, has also been very unwell and was in hospital for several weeks. However a newsletter has finally eventuated. The group is in the process of changing the URL to its website so it is more easily found by those searching for post polio help.

US Congress has proclaimed 2007 the "Year of Polio Awareness." Dr. Richard Bruno, Chair of the International Post-Polio Task Force, has nominated this month as "Polio Awareness Month". He lists many concerns, including polio vaccination awareness. In the past two years polio has been reported in five unvaccinated Minnesota children and in one unvaccinated Arizona adult. Unfortunately, the polio vaccine has been a victim of its own success, allowing parents to think that polio is "cured" and vaccination unnecessary. It is reported that 10% of US toddlers under three -- a million children -- are not vaccinated against polio, with vaccination lowest in poor cities.

Polio cases are increasing in India and Africa and appearing in previously polio-free countries such as Na

mibia. Not everyone infected with the poliovirus exhibits symptoms. For every case of paralytic polio, there are between 70 and 200 "silent carriers" of the poliovirus, says Dr Bruno.

"What will happen when a polio-infected individual from a foreign country lands in a densely populated city like New York, where an estimated 23,000 toddlers are unvaccinated? Every child must be vaccinated since America's next polio epidemic could be just a plane ride away."

Talking about PPS, he says Post-Polio sequelae awareness should not be forgotten, as it was 50 years ago: "There are still nearly two million North Americans alive today who had polio during the epidemics of the 1940s, 50s and early 60s. At least 70 percent of paralytic polio survivors and 40 percent of non-paralytic polio survivors are developing Post-Polio sequelae, unexpected and often disabling symptoms that occur about 35 years after the poliovirus attack.

"They include overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anaesthesia, cold and pain, and difficulty swallowing and breathing. Unfortunately, many polio survivors and health professionals are not aware that PPS exist and are readily treated by reducing physical over-exertion, 'conserving to preserve' polio survivors' remaining poliovirus-damaged neurons. Polio survivors and health professionals need to be aware of the cause and treatment of PPS."

***To finish on a lighter note: If you ever feel bad because you are slowed down in all aspects of life because of your disability, just keep this in mind: The early bird may get the worm, but the second mouse gets the cheese.***

***Have fun, Susan.***

## ***Polio Eradication Drive hits Trouble***

**Nigeria, which was expected to be free of new polio cases by the end of this year, has had a massive turnabout in its eradication programme and the oral polio vaccine is blamed for 69 cases of child paralysis. The World Health Organisation and the US Centre for Disease Control and Prevention jointly announced the setback last month -- although apparently they knew about it for some time.**

**Experts say the problem is due to the low number of Nigerian children who are vaccinated. The oral vaccine is used in developing countries because it is cheap and is easy to administer. It contains traces of the virus which can be excreted and spread in unsanitary conditions.**

**Officials now worry that the Nigerian outbreak could set off an anti-vaccine scare.**

The 20th annual general meeting of the PPSS in Hamilton went tidily with no additional nominations to contest any of the board offices for the coming year.

Ray Wilson, president for the past nine years, was re-elected but gave notice that he would resign at the 2008 AGM. Philippa McDonald remains vice-president, John B Munro continues as secretary, and the meeting decided that six would be the size of the board of management -- exactly the number of people nominated.

Previous board members Des Crabb (Bay of Plenty), Jenny Green (Otago) and Susan Kerr (Marlborough) were re-elected, and new members are Laura Ladkin and Edith Morris from Hamilton and Dale Smith from Whakatane.

The financial statement for the past year was approved -- although not without a query about an entry for "various" expenditure of more than \$1000 and some criticism of five members of the board going to Sydney in May for the Polio Australia "think tank" conference: Six members voiced concern from the floor that so many -- the three executive members and two more board members -- had gone on the trip. Speakers suggested that three would have been enough, that the Board needed to get down to grass-roots issues and

## **Board Members from Waikato and Bay of Plenty elected at AGM**

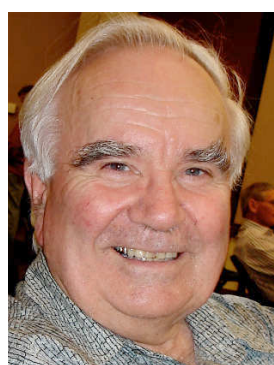
that it was "really important" to get copies of the presentations  
President Ray and secretary JB Munro explained the structure of costs, which included part coverage from New South Wales and some grant money left over from the March board meet-

ing when the PPSS hosted a visit from Mary-Ann Liethof from Melbourne.

"I'm prepared to write up a report for the whole visit, but New South Wales promised a printout which hasn't arrived," said Susan Kerr. Secretary JB said it was as a result of the visit that Dr Stephen de Graaff had been encouraged to come to the annual conference in Hamilton, but it was right that the move should be "challenged and questioned at the AGM". President Ray said he didn't think the visit was overkill: "We all learned from it. The debate was whether New Zealand would be part of the new Polio Australia model. I needed to go to open the Think Tank and introduce the others. It was very worthwhile."

Minutes of the 2006 AGM were approved as were the financial and president's reports. The society finished the year with a net deficit of \$929, compared with \$5579 the previous year, leaving accumulated funds of \$27,217.

***Below*** -- PPSS Board members, clockwise from top left: President Ray Wilson, Des Crabb, Jenny Green, JBMunro, Laura Ladkin, Edith Morris, Susan Kerr Dale Smith, and Philippa McDonald,.



# ***Exercise: Okay, but Take it Easy to Improve Muscular Function***

**Until recently, exercise was considered to have detrimental effects on strength in post-polio survivors. But Dr de Graaff says recent studies have changed that view.**

“Exercise has been demonstrated to be effective in the improvement of muscular function and an increased sense of wellbeing associated with performing exercise,” he said during his Hamilton conference presentation on services needed for polio survivors.

A non-fatiguing programme of exercise would provide isometric work for muscles with less than anti-gravity strength and an isotonic or aerobic programme for muscles with greater strength.

“Many can improve both muscle strength and cardiovascular endurance. To be avoided is an activity level that leads to excessive fatigue, joint or muscle pain or a sense of loss of endurance or muscle strength: “Initiate the exercise programme at a very low level of intensity and duration, with a gradual increase as the individual adapts to the exercise.”

On energy conservation techniques he said: “Do what you most want to do, plan activities for when you have most energy, respect the signs of fatigue you experience and stop before you become exhausted.”

Exercise formed part of an address on services needed for polio survivors, many of whom would have Post-polio Syndrome and others would be suffering from the late effects of polio -- including biomechanical dysfunction, orthopaedic discrepancies, over-use injuries, ergonomic inefficiency, personality

difficulties and functional deterioration with time and age. The prime personal challenges could include fatigue (89 percent), pain (86 percent), weakness (83 percent) and new atrophy (23 per cent)

Dr de Graaff defined the principles of disability prevention and management as prevention, early detection and intervention, partnership, goal-orientated rehabilitation plan, respect and dignity, and quality management.

## **Polio Rehabilitation Partners**

**A core team of rehabilitation specialists (similar to the main ones provided at QEH) were defined by Dr Stephen de Graaff in his outline of services necessary for polio survivors. It involves:**

- **Rehabilitation physician**
- **Physiotherapist**
- **Occupational therapist**
- **Social worker**
- **Orthotist**

**Other services he classed as desirable were podiatrist, psychologist, speech therapist and dietitian.**



**Stephen de Graaff (left) with Colin Gilmour of Tauranga (centre) and Hamilton lawyer Alan McAllan, at the PPSS conference in Hamilton.**

# PPSS Symptoms and Over-diagnosis risk

Post Polio Syndrome symptoms are seen now in 50 percent of polio survivors. This increased level of PPS indications -- till recently believed to be in the range of 35 to 40 percent -- was given by Dr Stephen de Graaff in his main address to medical professionals at the Hamilton PPSS conference.

However he cautioned that PPS tended to be over-diagnosed: "The term PPS has been used loosely by many consumers and even physicians to describe all new problems noted by polio survivors -- thus PPS is over-diagnosed."



He outlined the history of polio and defined PPS as an "otherwise unexplained constellation of symptoms" in patients who had paralytic polio. They were:

- New muscle weakness
- Muscle and joint pain
- Fatigue
- New muscle wasting
- Heat or cold intolerance
- Swallowing, breathing or sleep disturbance

The five criteria required for PPS were evidence of prior paralytic polio, a period of partial or complete recovery, gradual or sudden onset of progressive, persistent signs or symptoms, symptoms that persist for at least a year and exclusion of other causes. Dr de Graaff defined the difference between PPS and the late effects of polio -- which could include weight gain and age-related weakness -- in terms of advice on management of the symptoms. He also gave detailed analyses of the pathology relating to the poliovirus infection, physiological and clinical consequences, and factors affecting neurological and functional recovery.

In the management process he said the aim was to minimise deterioration in function, over time, by optimising the balance between muscle strength and endurance in relation to the burden of activity, and also by pacing and gradually decreasing daily energy expenditure.

Discussing medications potentially to be avoided in PPSS he listed beta-blockers, calcium channel blockers and diuretics, certain antibiotics (tetracycline and aminoglycosides), also phenytoin, lithium, phenothiazines, barbiturates, statins, benzodiazepines and certain anaesthetics.

## A Different Kind of Pain

**Hamilton orthotist Colin Storey (right) raised PPSS conference-goers' eyebrows when he said some polio survivors were among "the greatest pains" of his job.**

But he won their hearts in a frequently funny after-dinner speech when he said he people weren't patient enough to get their orthoses right: "It hurts to hear of callipers I've made being thrown into the cupboard". On the "pains" topic he described polio survivors as extremely stubborn and often uncomplaining: "They wear their callipers out. The joints wear out. The leathers wear out. Their legs change. Then they try on a new one and if it's not the same it's no good. People don't complain.

"You have to complain. As a group you need to complain -- to the right people. The Ministry of Health and the DHBs are putting in place the systems -- when you complain, it's the squeaky wheel that gets the oil. There are a few of us who care what's going on." Colin Storey is a third-generation orthotist whose grandfather started the hospital's boot and splint department in Hamilton. He first became aware of polio

at an early age when he was given the job of maintaining a calliper-wearing tennis star's trike.

"I spent five years training to be an orthotist and three years in technician training. Now there is no training in New Zealand at all and the nearest course is at La Trobe in Melbourne."

Colin worked within the health system until 18 months ago when he started his own practice, Orthotic House, in Hamilton. He is a lower limb paediatric specialist and has handled assignments as unusual as providing a theatre table mattress on which conjoined twins could be operated, and making a brace to hold the heart of an infant born with an external heart, until the rib cage was big enough to contain it.



## De Graaff on Pain Management

Do older people feel pain less severely than younger people? Dr Stephen de Graaff believes so. In the course of an eye-opening presentation on pain at the PPSS Conference he said the older generation tolerates pain more than his generation: **"You become more tolerant, you come to accept that it is part of you."**

However, he warned: "The critical thing is when to know it is time to do something about it."

In a wide-ranging talk about types of pain, reliance on therapy and the need for self-management, he said pain was unpleasant, it damaged tissue and was always subjective.

"Everyone has different forms of pain, but it is real. Sometimes pain comes and goes, such as after a particular movement. The big problem is persistent pain, associated with substantial disability, frequent use of health services and substantial use of analgesics. It is commonly associated with depressive symptoms such as lethargy, apathy, anorexia and insomnia. Your personality may change and your reactions may be stretched."

Dr de Graaff said if you tend to be negative, others around you tend to be as well -- possibly leading to a negative environment. Managing non-cancer pain started with thorough assessment then diagnosis and treatment. Physical and non-drug treatment should be started early . . . possibly exercise, hydrotherapy, heat, massage:

"We need to look into their environment to see what they can do and what they can't. Some people are quite open about their pain, others won't tell you about it. You as a group will initially deny it. Some will say 'okay', some will go rolling along. The challenge is getting people to accept their pain and self-manage it."

Self-management, said Dr de Graaff, started as simply as taking paracetamol when pain was moderate to mild -- and not saying medications are bad for you. He ran through pharmacological treatments -- Paracetamol and other analgesic options for initial use, more substantial drugs such as Tramadol and Morphine for pain persisting more than five days, and supplemental tricyclic antidepressants for night-time pain.

***De Graaffisms . . . . . "If someone says they're going to cure you, walk out the door."***

***"There is yet to be an exercise or therapy process that is right for everyone".***

***"Yoga teaches you to use different muscles and take control".***

***"Pilates . . . go to an expert who knows Polio, not one who treats movie stars"***

## Conference Sidelines

Vice-president Philippa McDonald was re-elected in absentia, due to a back-injury which put her in bed two days before the conference. Another Wellingtonian who missed the weekend, former board member Claudia Mushin, was also recovering from injuries.

Hamilton's Novotel Tainui seemed to fulfil nearly everyone's needs . . . valet parking, obliging luggage handling, good food arranged by the Hamilton PPSS folk, excellent rooms (you could check your bill on the TV!), a big patio chess set, and Sky City Casino next door. If anyone sneaked off to win a heap on the roulette wheels they kept very quiet about it.

Two travellers from Wellington found Taupo a deceptive stopover for an accessible mid-range motel room. They sought listings from the local information office, went to one on the list which, booked out, recommended the Chelmswood along the road. Checked into the "accessible" unit there which, though it had a lovely thermal pool, provided a novel concept of "accessible": Like a ranchslider door to get the wheelchair in. That was it. Lose a mark, Taupo.

On the road home, same travellers discovered a comparatively new oasis in what has been a SH4 eatery desert between Te Kuiti and Wanganui. A young couple from Auckland have moved to Owango and opened the Out of the Fog cafe. Good food, excellent Allpress coffee, easy music and an accessible toilet that is a wonder to behold.

How good to see more northern folk than usual attend PPSS conferences. One youngish man from Auckland hadn't heard of the national society before and was most impressed with Dr Stephen de Graaff's talks. And Graham Blackett from Te Awamutu, who also helped lower the average age of people at the meeting, described his first conference as "very helpful, positive, with a lot of information".

Well-known West Coaster Patsy Bell, from Hokitika, who has attended the annual conference since 1989, saw the Hamilton one as "really well organised" -- and as usual there were new people as well as many old friends.

Finally, the Conference dinner Menu: Entree, choice of smoked chicken/avocado salad or Caesar salad with smoked salmon. Mains, rack of lamb with herb/walnut crust or grilled salmon fillet. Dessert, chocolate fudge cake or fruit salad in brandy snap. Yum!



# Crash ended 50 years of Disability Inspiration

**Notable paralympic world record-setter Graham Condon, who survived polio as a child, died in a road crash in Christchurch recently. His specially-made hand-cycle was struck by a car driven by a 15 years old.**

The popular Christchurch councillor was a staunch advocate for community rights and services. Graham, disabled by polio as a pre-schooler, fought to get on top of his impairment. His older brother pushed him to primary school on a tri-cycle. He left school at 15 and within two years was on his way to sporting fame.



church support group. "Graham's involvement in the city as a councillor over many years may well account for the high degree of accessibility enjoyed by those with disability in and around the city. Graham was a person of whom most Christchurch residents were aware. Not everyone had been fortunate enough to meet him personally, but many of us had. His sporting and other achievements over many years brought him to prominence and endearment with the public."

Graham is survived by his wife of 35 years, Kathy, and two children, Craig and Andrea.

*Councillor Condon (far left) and as a wheelchair athlete.*

Graham was a member of the PPSS and reportedly started his medals hunt after being inspired by a disabled Irish priest who extolled the virtues of sport. He went to the Israel Paralympics in 1968 and represented New Zealand at many international events -- setting seven world, Olympic and Commonwealth records and winning 36 international medals. He made his name in pentathlon and discus events, and did marathons for enjoyment in his free time.

After retiring from competitive sport, Graham's drive shifted to the community and regional sport. He joined several committees and sports agencies, creating more opportunities for thousands of sportsmen and women. During his time with Parafed Canterbury he expanded the organisation from a monthly living-room gathering to a respected regional sporting body.

As a city councillor he distanced his disability from his politics, : "I see myself as an advocate, not an advocate for the disabled. I'm no crusader. I hate political correctness and what it has done for people's treatment of disabled people – political correctness wastes a lot of time."

Graham held the NZ Commemorative Medal for Services to the Community -- a complement to the QSM he received in 1981.

"All Christchurch Post Polio members extend their condolences to Graham's wife and family," said George Ross, paying tribute on behalf of the Christ-

## Polio Didn't Slow A Great Achiever

**Dick Potton didn't let severe polio keep him from a life of achievement. When he died recently aged 82 he left a legacy of great accomplishments. He founded Zip Industries and was involved in many business ventures in New Zealand and Australia.**

"He loved new adventures and risk-taking," said his son, noted photographer and publisher Craig Potton. "He lived believing you make what you can of your life through your willpower, dealing with the circumstances as they are dealt to you."

Mr Potton was born and raised in Nelson. He came top in engineering at Nelson College before leaving aged 15. He started out mining talc from the Cobb Valley and selling it throughout Australasia. Then he became involved in Nelson Electroplating, forerunner of Zip Industries.

He caught polio aged 28 and it left him with permanent disabilities and then post polio syndrome in later life. His entrepreneurial drive was undiminished and he had a wide range of business interests. He also travelled the world with his wife Rhoda who predeceased him by 12 years.

# LONG-TERM DISABLED? HERE'S A GUIDE TO EQUIPMENT THE 'SYSTEM' MAY PROVIDE

This summary of disability services from the Ministry of Health is a basic outline of what's available through the "system". The Ministry guide outlines clearly that if you're finding everyday activities difficult because of physical, intellectual, sensory and/or age-related disability, help may be available.

Qualifying criteria are longterm (at least six months) disability, inability to do some everyday activities safely on your own, and no ACC cover. You must also be a New Zealand resident or be from a country that has a funding agreement with NZ.

To get help you need to contact a specialised assessor -- who can be an occupational therapist, a physiotherapist or speech, hearing or vision professional. Reach them by asking your GP for a referral, contacting Accessable (0508 001 002) or Enable Information (0800 17 1995), contacting a private assessor (who you will need to pay) or a support organisation. The assessor, usually an OT, looks at your situation and discusses options for you. If equipment or modifications are recommended, the assessor sends an application to Accessable or to Enable NZ. Not all applications are approved and other options can be advised by an assessor.

A great variety of assistance is available to eligible people. It includes provision of sticks and walking frames, wheelchairs, shower stools, hearing aids and other devices. Sometimes items such as crutches may be issued only by orthotics providers. The help providers can supply handrails and install ramps to your house, modify doors and shower access, and they can also arrange vehicle modifications. You might have to pay part of the cost of house or vehicle modifications. In rare cases, some support is available to help with buying a vehicle.

All equipment is provided on loan for as long as you need it. The "providers" are Accessable, if you live in Auckland or Northland, and Enable New Zealand for the rest of the country.

Useful contact information: Accessable (0508 001 002), Enable NZ (0800 17 1995), MoH Disability Services Directorate (0800 DSD MOH)  
Websites (all www.): [accessable.co.nz](http://accessable.co.nz), [enable.co.nz](http://enable.co.nz), [disabilityfunding.co.nz](http://disabilityfunding.co.nz), [moh.govt.nz/disability](http://moh.govt.nz/disability), [moh.govt.nz/districthealth](http://moh.govt.nz/districthealth) boards

## We Say

- ⦿ Please note the story says "may provide". Sometimes the system seems unresponsive.
- ⦿ Occupational therapists sometimes don't appreciate polios' predicament, and give a low priority until polios are falling down and hurt.
- ⦿ Enable often is blamed when the real problem may be the OT's assessment of your application.

## *New Work and Income Disability Position*

Anne Hawker of Wellington has been appointed to the new position of Principal Disability Adviser at Work and Income. Previously she was strategic rehabilitation programmes manager at ACC. At Work and Income she heads a team of advisers in 13 regions: "It is recognised that regions are different from each other in various ways, such as regional incomes, and nationally it is the aim to provide some consistency," she told *Polio News*. She is an advocate for smaller disability organisations joining with others of similar nature to gain a stronger voice on rehabilitation issues.

Anne Hawker is president-elect of Rehabilitation International, the New York-based international disability rights organisation, and will succeed Michael Fox of Australia next year. New Zealand has had one other RI president, John Stott who headed the 85 years old organisation from 1992 to 1996.

**For your information:** Work and Income at present provides a range of assistance within the Disability Allowance -- which is income-tested but not taxed. A doctor needs to complete part of the application form. The assistance is to help meet continuing, regular costs incurred because you have a longterm disability. Help is provided for costs such as doctor and prescription costs, extra clothing and travel that may arise from your disability. The maximum disability allowance is \$52.38 a week. Pre-tax income must be under \$742 a week (married) and \$510 single, with other limits for sole parents.

# TOOLS, TIPS, TRICKS



## Chair and Scooter hoists

High-tech Bruno-branded hoists to swing a wheelchair or scooter aboard a vehicle are gaining popularity in New Zealand. They operate from a car or wagon's electrical system and although they're securely bolted into place they can be moved by an installer from vehicle to vehicle. The most popular of around 25 Bruno lifts on the market are the AWL 150 wheelchair lifter, the 325 Space-saver (photo) and 350 Offset scooter hoists. There are models for larger "people mover" vehicles. The 150, rated to lift up to 25kg, uses an swivelling arm with an electric winch to move a manual wheelchair into and from the back of a station wagon -- or a hatchback with rear door opening deep enough to accommodate it. The 325 and 350 (maximum 90kg and 80kg respectively) use heavier arms to load a folded scooter into the boot of a car or the back of a wagon. Prices from the Auckland distributors, Mobility for Independence, range from \$2811 for the 325 to \$3811 for the 350, including \$500 installation and GST.

## Flat Tyre Helper

Many polios find tyre-changing difficult, specially when having to undo tight wheel nuts with one of the small wheel wrenches provided in modern cars. Two tips: Buy a cross-braced wheel spanner to keep in your spare-wheel well -- it gives much greater leverage. Or acquire a 15-inch length of 20mm pipe to fit over your car's standard-equipment spanner.

## Warm Socks

Great idea, but we can't find a retailer in NZ for these battery-heated socks. They're \$US20 to \$US23 a pair from one of

America's biggest outdoor gear suppliers, Cabela's in Nebraska which has stores all over the US, Canada and Mexico. They're



hand-washable and made from wool/acrylic/nylon. Two models are available -- these "wader" socks which have a remote D-cell battery, and a cheaper

"boot" style carries the battery in a pocket clipped to the top of the sock. Battery life is five to six hours on alkaline, two to three hours on rechargeables.

## Safe when you can see



### Seen one of these puppies?

It's a brilliant little LED headlamp used by cavers and trampers and cyclists. It's excellent for small scooters that don't often come with headlights. Remove the elastic head-straps and you have a bun-sized torch that clips into scooters' basket-brackets. If the bracket's too big, you can tape up the lamp holder to fit snugly. The lights go for ages on three AAA batteries and have three or four strong white

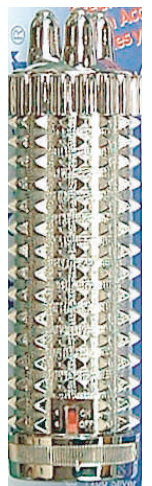
beam options. Around \$20, sometimes on special for \$9.

## Great Reading

*Family Care* is a quarterly must-read magazine with lots of disability interest. Available at Disability centres and from Family Care NZ, PO Box 133, Mangonui, Far North 0442.

## Korean Vibes

This little, vibrating "mini acupuncture" roller vibrates strongly, can be rolled in the hands to warm them with 230 little points that stimulate circulation. Claims to improve blood flow and stimulate nerve endings to "positively affect" many parts of the body, based on the concept that the hands are keys to broader health effects. Looks like a mini road roller, comes with a comprehensive user guide, runs for a long time on two AA batteries. Widely sold overseas. Our one came from travelling stallholder Mr Jae. Prices range from \$35 to \$45.



## Tight Shoes?

Specially made shoes are among the funded aids provided through orthotists, however polio people who wear one calliper sometimes buy off-the-shelf shoes and have one of them stretched by a shoe repairer. This applies only to wearers with one of the slip-in-shoe callipers that need a tad more space than the other foot. Stretching shouldn't cost more than about \$7 and usually it takes half an hour on the stretcher, using a suitable shaper.

# GOOD RESPONSE TO *POLIO NEWS* SURVEY

The Polio News survey of readers produced an excellent response -- thank you! Within three weeks of the August issue appearing in the letterbox more than 11 percent of readers had sent in survey sheets. More came as late as after the conference, for a total of 93 returns. A major survey company says this is a satisfactory level -- indicative of members' preferences and also their status with regard to degree of disability and use of mobility aids.

In addition to readers' rating of topics in *Polio News* the responses disclosed aspects of health treatment and reliance on various disability aids. Almost 75 percent of respondents use some form of mobility aid. While users of walking sticks and crutches form the biggest group many polio survivors use a variety of aids, depending on their needs at the time. Some for example use a walking stick or crutches around the house and a folding wheelchair or a walking frame when out and about.

Nearly 25 percent of people who've had polio have no need of aids. Some might never need them. Others are keeping a close eye on their options, should they join the still growing percentage of people affected by Post-Polio Syndrome many years after the initial attack.

Of topics frequently appearing in *Polio News*, most interest is expressed in medical aspects of polio and disability health issues in New Zealand, followed by new disability products and overseas polio news. Personal polio stories rated fifth choice in the survey.

PPSS Board comments on topical matters rated tops in the survey section on PPSS-relevant subject matter. There was considerable interest shown in what Board members had to say in the August *Polio News* about their visit to Sydney and the new Polio Australia project. Second and third respectively in this survey segment were editorial comment and presidential comments. Letters to the Editor figured in fourth place, then support group news -- a topic which seemed to polarise readers: The interested ones gave support group news a very high rating; the not-so-interested marked it down.

## ***Travel interest***

Nearly a third of all survey respondents showed some interest in travel within NZ -- accessible modes of travel and accessible accommodation. A few, not nearly as many, expressed interest in accessible overseas travel.

## ***Many suggestions***

As well as answering survey questions, many readers made a range of comments on *Polio News*. One suggested larger type, two asked for it to be emailed, two sought more humour, many said keep it straight to the point of polio topics.

## ***Treatments. . .***

On the medical and rehab treatment front the great majority of polios are happy with their GP and/or specialist. Likewise with physiotherapists -- around one third of respondents have had some experience of physio treatment and nearly all have been happy with the results.

Occupational therapists and orthotists have been seen respectively by just under and just over 25 percent of polios. About one in four of those people were not happy about the results of their treatment -- a few quite positively unhappy.

There were critical comments about waiting times for OT and orthotist treatment, OT's lack of awareness of polio and also about Enable's slow handling of applications.

Rotorua's QE Health staff were mentioned favourably by several responses in the medical and rehab treatment-section of the survey

Suggestions that *Polio News* might publish a support groups list and also minutes of board meetings came at the bottom of the segment, indicating little interest in these subjects.

Of other *Polio News* topics, anything relating to disability services in New Zealand rated highly. Most readers were happy to see the same level or more of overseas polio network news. Household and personal mobility hints rated highly, with rather less interest in scooter and wheelchair maintenance. Computers and the internet seem not to generate a lot of interest among most readers. About 26 percent would be happy to see less about computers and the internet and 25 percent more -- so it is hard to get a fix on the percentage of computer users. But at least one in four use computers or are interested to learn more about them.

**The healthy level of response to the survey will make it easier to tailor the contents of future issues of *Polio News* to readers' interests.**

# PPSS SUPPORT GROUPS' NEWS

## ***Northland Christmas***

Our group will meet next for our Christmas luncheon at the Stage Coach hotel in Kamo on Wednesday 14th November at 12 noon. All welcome! It was lovely to meet up with many of you at Conference in Hamilton. I'm sure we all benefited from the great knowledge and advice given by Dr Stephen de Graff, and it's been good to pass back this valuable information to our members. Our last meeting was again out at Parua Bay at Shirley and Mac MacLucas's beautiful home, where the breathtaking view always takes precedence over any business matters! Our very best wishes to you all for the forthcoming festive season. -- **Ruth Inglis.**

## ***Taranaki Travels***

**Shirley Hazlewood** has been visiting members and going to forums for the disabled. She and Tony went to the Hamilton PPSS conference -- enjoyed it, but found the food and parking expensive. The group's Christmas break-up will be at Cobb and Co at 11.45am on December 8.

## ***Dietitian at Lower Hutt***

Seventeen people attended our last meeting. Jan Milne, a dietician, came and spoke to us and answered questions. Unfortunately Frank Andrews was too busy to come along, but I'm sure we'll catch up with him later. Our oldest member Frances Sykes has knitted her 98 teddies and also about 30 hats for children. They are winging their way over to Russian orphanages, arranged by a Lower Hutt family who have adopted two Russian children. Frances is looking for more wool -- if anyone has some to spare we would be pleased to hear from them.--**Judy Cameron**

## ***Disability aids at Wellington***

We had a wonderful attendance at our third meeting. There were 20 people present, including two members of the Lower Hutt Group. We now have 23 members altogether. Jo Maling from The Disability Information Centre in Petone gave a most interesting and informative talk about the service that her centre offers people with disabilities. She brought many articles with her and, it being a cold day, her very warm possum fur gloves and socks were of particular interest. One of her more interesting aids was a nifty little contraption that attaches to a walking cane and enables the owner to attach it to a bench, table or counter top, thus

avoiding the cane falling to the floor with a clatter as mine often does! We had a lot of laughs over details and photos of a chair which is like a Lazy-Boy and propels the occupant speedily to their feet with the flick of a switch. This comes at a price, of course but many of us liked the idea! We plan to have a Christmas lunch on Saturday, December 8 and we hope that other local groups will join us to celebrate. -- **Claudia Mushin.**

## ***Christchurch Year-end Events***

With several end of year events being planned by the Christchurch group, there can be no doubt that Christmas is nearly here. First on the list is the annual hot spring holiday at Hanmer for those lucky enough to have booked early and this event is underway as I write. In November our final meeting for the year will feature musical entertainment, Christmas hamper raffles and a special sales table. An evening Christmas Dinner function on December 17th will finally bring the year to an end. We again engaged a wheelchair bus in August for an outing to Methven and in September attended a very enjoyable daytime concert by entertainers called Operatunity. If they ever visit your district be sure to book a seat. For about \$20 you get a ninety minute show and a light lunch. They perform all around New Zealand with a different show several times a year. Try their web site for details. Merry Christmas to all. -- **George Ross.**

## ***Spring in Nelson***

Spring is looking glorious in Nelson as we look forward to Christmas. Where has this year gone? We sadly record the passing of our member Courtney Lawry, one of several we have lost lately. Paul and I shift house on November 23 but our phone number should remain the same. Our end of year lunch will be at El Taverna Restaurant, 183 Queen Street, Richmond. Do try to come -- if so advise Rex (54 77043) or me (545 1030) -- and a very happy Christmas to all. -- **Jenny Kissane**

## **NEW YEAR DEADLINE**

**Deadline for March issue: 15 February 2008**

**PLEASE NOTE: Polio News Editor Jim Webber will be moving house in January to 357B Kapiti Road, Paraparaumu Beach. email and phone contacts will remain unchanged.**

# NZ Immunisation Schedule Changes for 2008

NZ children who turn 11 next year will no longer need vaccination against polio, according to the just-released national immunisation schedule for 2008.

Changes to the schedule mean they will already have received the recommended four doses of polio vaccine. The main change is the addition, from June next year, of the pneumococcal vaccine Prevenar, for all babies born from 1 January 2008. Babies will receive three injections --at six weeks, three and five month visits.

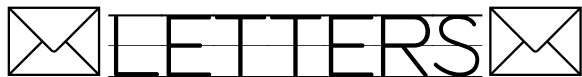
One vaccine will protect against six diseases (diphtheria, tetanus, whooping cough, polio, hepatitis B and Haemophilus influenzae type b). Babies will also receive the meningococcal B vaccine and the pneumococcal vaccine.

"Parents do not need to worry about their baby receiving vaccines against eight diseases at one time as a baby's immune system responds well to multiple vaccines at one visit. The Ministry's advice is that it is safe and effective for babies to receive vaccines to protect against eight diseases at the same time."



## Conference DVD Available

Noel Morris of Hamilton (above) recorded conference addresses and questions on video. Order from him online at ([www.Faithnet.co.nz/tapes/pps07](http://www.Faithnet.co.nz/tapes/pps07)) or from Faithnet, PO Box 12357, Hamilton. DVDs are \$30 for each of the four De Graaff presentations or \$80 for the set.



### Statins

Reading the latest newsletter (Statins, August issue) I thought I would tell you that my doctor last year gave me Lipex, one of the statin pills for high cholesterol. After three or four months I could hardly drag myself around. After a blood test I was taken off it and discovered my liver so badly affected it took three months to return to normal.

**Phyllis Larkin (Invercargill).**

### Balance

I must congratulate you on the well balanced newsletter. Starting from page one there's enough room for the name, the rest is good reading. Many newsletters waste so much space on this page. Gloss paper would be good but for a \$10 subscription, no complaints.

**Peter J Fox (Tauranga).**

### Exercise

I contracted polio in 1948 aged 19 but was let out to get on with my life. I played rugby at home and with

the RNZAF -- enjoyed my flying, specially in Harvards and Mustangs. Had to have left hip and right knee replaced, then both shoulders. My problem showed up in my right hip -- I couldn't lie on it at night, tried all sorts of "cures" but none worked. My orthopaedic surgeon may have had a message from Dr Liz Falkner: Within 12 months he put me under a physio for apparent muscle weakness in my hip. A set of exercises was provided which have been marvellously effective. I can now sleep on my right side for half the night -- I could not tolerate it, before, at all. So I'm a very strong advocate for spreading the "word" among the medical fraternity.

**Mike Daniell (Masterton).**

### Flying

I would like to hear if other polio people have the problem I have when flying Air New Zealand since they moved more seats into the plane. Because of my condition I require extra space to stand up or sit, and once seated no-one can pass me. I now feel I can not fly anymore. I have written to Air NZ and they told me my letter would be passed on to the Manager of Interiors for her consideration. I have no problem getting to a seat, but there is not enough space to get in or out of it.

**Eileen Welsh (Christchurch).**