

Readers' Letters

Polio since 1937

I was interested in Patsy Bell's polio anniversary, mentioned in the May issue. I "celebrated" my 70th recently, having got polio in legs and back on May 3 1937. I've used crutches since 1944, but am in the process now of breaking myself gradually into wheelchair use.
John Dawson (Nelson).

Serious swallows

Your item in May issue reminded me of grandma's advice to us children. If we were seen gulping at the table we were told "Chew properly - take your time!" That might still hold good and help with these polio effects.

C Taylor (Napier).

Slogans

Thanks to everyone who suggested PPSS slogans. They included the

following: "Every Child Vaccinated, Every Polio survivor -- and doctor -- Educated" (from the International Post Polio Task Force) (Gisela Sonntag (Whakatane), "Polio Limited - Survivors unlimited" and "Polio Support . . . More than a Calliper" (Carol McKenzie Hamilton), and "Post-Polio-Post" or "Polio-Postings" (Terry Stewart Waikanae).

Computers. Love or Hate them

(Continued from page 10)

Polio News is written and assembled into pages on Apple computers that also insert photographs where required. Each finished issue is sent by email to the printer, who "downloads" it to Windows computers for printing. To that extent the two systems are compatible. There are some basic differences. Standard Apple computers can "read" text sent from Windows computers, but it doesn't always work in the other direction.

There are also two kinds of monitor -- the long-running CRT (cathode ray tube) screen and the slimmer LCD screen, which has graduated from laptop to occupy a smaller "footprint" on the desktop. Some people find CRT computer screens harder on the eyes than LCD screens.

If you're buying a computer, buyer beware was never more appropriate. A used computer might be okay if you know its history or it has some kind of warranty. But try not to buy "cold" on the appeal of a cheap price tag. Many computers that end up on the second-hand market are there because of either problems or dated systems. You might strike it lucky at say an auction of surplus company equipment, but bear in mind that the staff might have had first pick of unwanted assets.

New computers have never been as cheap as they are now. They're fast and full of tricks, packed with potential that many users may never use. But there's no such thing as a "simple" computer. Even if you use your computer only for emails, keeping household lists, printing out birthday cards, writing your memoirs, storing your digital photos, playing the occasional game, looking up some information on the internet . . . as you become familiar with it there's no doubt you'll want to explore its many capabilities.

Talk to friends with computers. Take a test-drive. Try the feel of them. It's a little like buying a car -- the sales staff will be as sales-focused as the best of them. If you want to send them away to their reference resources while you browse, ask for a profile on the impact that various brands have on the environment. The more modern a computer, the easier it is to dispose of later on without adding to toxic waste.

This is a simple overview. Once you move into computers there are amazing numbers of ways to use them. Broadband, which enables you to access internet-based material very quickly, is gaining customers rapidly -- motivated also by freedom from New Zealand's globally-slow "dial-up" services.

Whichever one you use, you'll have greater ability to listen to music and to audio such as Edith Morris's interviews on Hamilton's Access Radio. Relevant sites to look up include Eldernet, which focuses on services for older people in New Zealand and includes a database of NZ rest, residential and retirement homes, and SeniorNet, a national network of learning centres and computer assistance for the 55-plus age group. Addresses for these websites are www.seniornet.org.nz and www.eldernet.co.nz. The Edith Morris website, which links to the PPSS Waikato support group website, is www.catchword.co.nz.

The New Zealand Post Polio Support Society's website situation is in a state of change at present. The "official" PPSS site that was listed in past newsletters has been replaced by a more up-to-date site which is hosted by the NZ Organisation for Rare Diseases. Its address is www.nzordgroups.org.nz/postpolio.

Whether you use a home computer or one at your local library, **Polio News** with full colour photographs is a mere click or two away.

Compensation for polio survivors -- in Israel

A radical new law compensating polio victims has been approved in Israel where there are some 2500 polio survivors. It provides for lump-sum payments and lifetime monthly payments, and approves Israeli government coverage of all costs of treatment and "medical instruments".

Israel's main polio epidemic was in the early 1950s, a few years after Israel was established and a time when many immigrants arrived in the country where health conditions were poor. Doctors of the time had little knowledge of polio and often gave inadequate treatments.

The Association of Polio Patients in Israel said that over the past two years negotiations with the Knesset (Israel Parliament) health committee had focused on com-

pensation and on the cost of future special treatment not covered by Israel's national health scheme.

The new "Law of Compensation of the Polio Victims" was passed on March 19. It agreed to make lump-sum payments based on permanent disability ranging from \$16,700 for up to 75 percent permanent disability to \$40,115 for over 95 percent PD.

Lifetime monthly payments are determined by a sliding scale based on half of the average monthly salary in Israel, which is \$2500 at present. A polio victim with over 20 percent PD receives the full monthly payment of \$1250. A polio survivor with less than 20 percent PD gets a lump sum payment instead of monthly payments, based on the degree of disability. At 15 percent this works out at a lump sum payment of \$13,000.



Two Chairs -- Spot the Difference?

Easy, really: One you push, one you drive. Heartway's "attendant" powerchair, the Tango (right), operates forward up to 5km/h with an attendant at the handles and up to half-speed in reverse. Travel range per charge is 30 kilometres. Carrying capacity is 136kg and a safe climbing angle of 12 degrees is specified. The Tango is fitted with seat and heel straps and it looks modern, with moulded lower bodywork in a choice of colours. Cost? \$5290 from Mobility Wellington.

The Go-chair (left) is getting a lot of interest at Pride Mobility agents and some disability centres around the country. It's a neat alternative to the bulky basic standard powerchair provided through the health funding system. Features include high manoeuvrability and light weight, attractive and user-friendly seat and controller and four-piece take-apart design for carrying in the boot of the car. Heaviest piece, rear wheels and motors, weighs 16.5kg. Price varies in the \$2850 - \$3000 range.

RESTLESS LEGS?

Effective medication is now available from GPs for "restless legs", says Dr Liz Falkner with specialist medical advice from Wairarapa Hospital: "It may help the cramps polios get, which is due to our neurological damage." The drugs are:

Ropirinoles 0.25mg to 4 mg at night. Current drug company name is Requip (usually used in the treatment of Parkinson's disease).

Clonazepam 0.5 - 2 mg at night. Current drug company name is Rivotril. It is a benzodiazepine and so can cause muscle weakness, also dependence though this is seldom a problem. Don't take alcohol when taking clonazepam.

Lioresal, initially 0.5 mg at night though this may be increased considerably. Current drug company names Alpha-Baclofen and Pacifen. GPs have to have specialist approval to prescribe it.

All drugs have a range of medical contra-indications, side effects and drug inter-actions which mean they may not be appropriate for any one individual.

Support Groups News

Polio Leaflet Drop

We hope all in the cold and snowy south have managed to get through the winter with no slips, slides or falls. Our members here in **Northland** have kept close to home through the winter. Some of us did get together for an enjoyable luncheon at Cobb and Co in June and our next meeting is our AGM in August.

Some of our committee have lately been stuffing envelopes for our recent publicity blitz: We packed the envelopes with the green "Have you ever had Polio?" leaflets and sent them to all doctors, dentists, medical centres and Citizen's Advice Bureaus listed in the front of the phone book. We stamped our contact details on them and at least one of our new members found us through the leaflet rack at his doctor's waiting room!

Envelopes? We apply to Lottery Seniors and Community Post for funding to produce and post our bi-monthly area newsletter to keep country and house-bound members in touch with meetings, speakers and information, and to educate members and the general public about PPS and how to cope with it. Our applications have never been declined.

All this publicity can be done from the comfort of your armchair. At least we feel we've done our bit for this year! Any group can do it, and we could get all of New Zealand covered!

Ruth Inglis.

Literary Lunch

Thirteen people enjoyed the **Eastern Bay of Plenty** support group's lunch at Whakatane RSA and we went afterwards to the library. The new head of the library explained to us how it operates and how to get the best use out of it. Issues like accessibility and the advantages of videos and audio tapes contra DVDs and CDs for senior clients were discussed.

A request from a client instigated an internet search about polio survivors undergoing surgery. This is a topic many of the ageing post polio clients are facing and there are specific complications that may occur for polio survivors.

The article "Preventing complications in polio survivors undergoing surgery or receiving anaesthesia" from Dr Richard L Bruno, an international authority in post polio matters, was presented to the support group. It was agreed to send a copy to all members with the advice to discuss this with their doctor and to add it to their medical file.

In June the AGM was attended by 13 members and there was no change in officers. We are very pleased

to hear that the national conference and AGM of the PPSS will be held in Hamilton, where local members will have much easier access than the usual venues in Wellington or Christchurch. I look forward to seeing many of you there.

Gisela Sonntag (Field Officer)

Musical Treat

Winter has visited **Christchurch** and that means frosts and days when you are glad to remain indoors. It can mean more, too; ask Christchurch members Noelene and Kevin about burst water pipes and they'll tell you roll on global warming! The cold seldom deters members from attending monthly meetings however, as the warm, spacious meeting room is a nice place to spend a morning with friends. Recent meeting highlights include delightful entertainment by a musical group and a demonstration of EZloader, which stores a wheelchair in the rear of a vehicle and delivers it, at the flick of a switch, to the driver's door.

Good use continues to be made of the local wheelchair bus and it recently took us to Gunyah Lodge, in the Canterbury foothills, for lunch. The annual games afternoon at Kaiapoi was a recent success.

George Ross

Helpful "Chat-and-Share"

Mid-winter lunch in **Nelson**, on a cold, sunny day, was a friendly "chat-and-share-views" session which solved a few problems and was helpful to many of us. Further to the comment in the last newsletter that "the message wasn't getting out in Nelson", Rex Wastney points out that the leaflets he distributes to doctors and other venues give only the Oamaru contact address. Denis used to refer inquiries back to us but we don't get that now. However information is still left at the CAB, Health Board, Physio Dept and surgeries and from these we still field some queries. Rex and I had a most productive meeting with our CCS and they have agreed to make space to store all our data at the CCS rooms. A major resource includes videos, books (including Bruno's "The Polio Paradox") and information leaflets. I hope many of you can attend the Hamilton conference to hear Dr Stephen de Graaff who is a splendid speaker.

Jenny Kissane

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PRESIDENT'S ANNUAL REPORT 1st July 2006 - 30 June 2007

Greetings to all: My thoughts go out to those who have had a bereavement or illness within their family circle. We particularly remember the passing of Denis Hogan last November. He served our Society and its members for something like 15 years, and his knowledge of things "Polio" will be hard to replace. To Helen and Joan Radburn, whose husband and carer Tom has also passed away, we offer our sincere sympathy. As we ourselves age, so we are called upon more and more to identify with those either mourning or involved with ill health.

Funding applications: The current year has had several successes more especially within the funding plan. As usual we lodged applications with Lottery Community Grants and the J. R. McKenzie Trust and benefited from both in the amount of \$15,000 -- this on top of our annual subscriptions. Following the invitation to Jeannie Warnock, a descendant of Sir Thomas and Lady Duncan, to attend last year's AGM in Wellington we formally sought financial assistance from the Duncan Trust to hold a board meeting in Wellington, including an invitation to Mary-Ann Leithof from Melbourne to attend. We were rewarded with funding to carry out this plan and we record our heartfelt thanks for this support. One important outcome from that meeting was naming the Board members who would travel to Sydney to attend the Australian Think Tank in May.

2006 Annual Meeting: The Brentwood, the most suitable venue in Wellington, was well designed to allow attendees to take in the arranged programme in September. However it seems not to matter what topics are selected by the organisers there are always some folk who would have preferred other topics.

Board meetings: The bi-monthly tele-conference meeting agendas usually take between 90 and 120 minutes to work through. They are not an ideal way to conduct meetings but are the least expensive. In November and January we planned the March face to face meeting which was a rarity for us. I extend to those who have been Board members during the past year my thanks for their dedication, time and energy. To Claudia and Cormack, who stepped down during the year, best wishes for your time ahead.

Sydney "Think Tank": The time spent by the team who visited Australia in May was without exception a very big learning curve. The problems facing the separate states are very much like those that face us with the 21 District Health Boards. When one considers that Victoria and Western Australia have support systems in place that do not occur in the other states, it seems like a copy of that which exists between Queen Elizabeth Hospital and most of the DHBs, thanks to the Ministry of Health. The big plus to come out of the Think Tank was Australia's national association which will be charged with seeing the same conditions exist across the continent. We will watch progress with interest. There was no hint of a take-over of our independent society, and nor could we officially be part of it -- an agreement that was shared by all.

Personally, I felt privileged to have my expenses to attend funded by Polio Network through the New South Wales Association, and would like to place my thanks on record. This proves clearly that we are considered to be part of the greater picture. I fully supported taking Philippa, JB, Susan and Jenny to give them an opportunity to meet and have open dialogue with their Australian counterparts.

Home Based Information: As we plan for the coming Annual Meeting and Conference in Hamilton, I am pleased to note that we invited Dr. Stephen de Graaff to come over as a keynote speaker. This was possible as he will visit friends in Matamata at that time. His input at Hamilton should not be missed by any survivor able to attend.

Polio Library: I have been given the task of caring for the books, leaflets, video and audio tapes previously in the care of Denis Hogan. I hope that I can serve the Society as well as he did. I have yet to check the list against that previously published by Denis in *PolioNews* to see if there are any changes.

Group Leaders?: As with many groups of volunteers the number who just want to be members far outweighs those who devote the time and energy to lead the organisation. So I put the question "Are You A Leader or a Passenger?" This Society needs leaders -- like YOU? Please tell someone if you would like to be considered for your local group or for the board of management. The ageing process has the effect of taking people out, who perhaps would have like to have stepped down earlier. It would be a pity to have people willing and yet not to know about their ability or interest. I look forward to seeing many of you in Hamilton in September.

Ray Wilson, President, Post-Polio Support Society of NZ.

HAMILTON CONFERENCE DETAILS

The 2007 annual general meeting and conference of the PPSS of NZ Inc will take place at the Novotel Tainui, Hamilton, on Friday, Saturday and Sunday, 14 to 16 September. The organisers expect a record number of members and others attending because of the central North Island location and also the visit of Dr Stephen de Graaff of Melbourne. Dr de Graaf is a noted polio specialist in Australia and made a considerable impression on the New Zealand PPSS group who heard him at the Sydney "Think Tank" conference in May.

"We expect perhaps 80 to 100 attending, among them some health professionals on the opening day when Dr de Graaff's addresses will be aimed at that level -- although of course members will also find the topics of interest," said an organising spokesman for the society. The Novotel is a four-star hotel in Alma Street. Its bookings number is 0800 44 44 22. Dr de Graaff's topics on Friday, 14 September, are "Polio, the legacy" (10.30am) and "Resources necessary to care for polio survivors" (1.30pm). A question time is scheduled for 4pm. The conference dinner takes place on Friday night. The AGM of the society is from 9 to 10am on Saturday followed by a talk at 10.30am on pain management and, at 1.30pm, an address about medications and polio survivors. On Sunday Dr de Graaff is giving brief one-to-one interviews for PPSS members and there will also be a meeting of the PPSS board of management.

Tips and tricks

Useful **warming pads** for portable cold-weather heat are called, appropriately, "Heat Me". They're plastic envelopes filled with sodium acetate. A little metal "clicker" magically heats them in seconds to 57-degrees. The pad we tried stayed warm for more than an hour. You have to boil them to "re-set" by re-liquefying the contents. They range from \$10 pocket warmers to slipper warmers and \$70 biggies, with velcro belts, for back and shoulder heat. See them on www.heatme.co.nz.

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Eco **light bulbs** which have been promoted recently are proving popular with people with disabilities. Reason: They last up to 10,000 hours, much longer than normal bulbs, so don't need changing so often . . . which can be a real problem for those of us who can't hop onto a kitchen chair.

* * *

If you are using one of those mini mobility scooters powered by a pair of 12-volt 12amp **batteries**, are you having trouble with battery life? Could be that you're using the scooter so frequently, including sometimes during the night, that your batteries aren't getting good long charges. Think about buying an additional pair and having connectors made up to charge them, using

the scooter's charger, for seven or eight hours at a time, or overnight. Then switch them around every two or three days.

* * *

On the same topic, be cautious about small, light-weight chairs and scooters that purport to do more than serve as indoor transport. Standard accessible **ramps** are graded at 12 degrees. Many of the littlies are rated for eight degrees. If the brochure doesn't show it, they probably won't do it. The smallest scooters and powerchairs use a pair of 12volt/12amp batteries -- with a replacement cost of \$45 to \$85 (best quality) each.

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Ever had that sinking feeling using your walking sticks or crutches at the beach? "Unifoot" ends for walking sticks and crutches solve the problem of beach walks. They can cost up to \$40, from disability resource centre shops. There is another, cheaper, version from the same source which has a smaller triangular tip, like a webbed foot. They look as if they would be good for soft and stony surfaces.

ODD FEET SLIPPERS FOR SALE
Alpine style, soft knitted tops, fluffy wool
inners, waterproof slip-proof soles.
Left foot 25 cm Right foot 26 cm. \$15.
Phone 07 855 4282

Polio News Survey

Here's our first-ever survey. It'll take you only a couple of minutes or so to tick the boxes. Please fill it in and help *Polio News* to respond to your likes and dislikes, interests and preferences. By way of explanation we've presumed that your interests focus mostly on polio and post-polio topics and items that flow on from them. But we're open-minded about this. If you wish to know about fishing or flying backpack aircraft or searching for new stars . . . we'll try to find experts who can write about such things from a mobility-challenged viewpoint!

Feel free to remove this back page of your newsletter and send it to the Editor -- or, if you happen to be heading for the PPSS conference in Hamilton, hand it to him there.

Please rank the following newsletter topics in order of your reading preference by putting one to four ticks in each box

Polio-related medical	<input type="text"/>
Personal polio stories	<input type="text"/>
Overseas polio news	<input type="text"/>
New mobility products	<input type="text"/>
Disability-related health issues in NZ	<input type="text"/>

Are you happy about your present health treatment? (tick if applicable)

Your GP and/or specialist	<input type="checkbox"/>
Physiotherapy service	<input type="checkbox"/>
Occupational Therapy assessment	<input type="checkbox"/>
Orthotics services	<input type="checkbox"/>

Do you use one of the following? (tick which ones)

Calliper or callipers?	<input type="checkbox"/>
Walking frame?	<input type="checkbox"/>
Walking stick or crutches?	<input type="checkbox"/>
Manual folding wheelchair?	<input type="checkbox"/>
Powerchair?	<input type="checkbox"/>
Mobility scooter?	<input type="checkbox"/>

If you use any of these aids, were they provided through the health system?

YES/NO

Can you show the following PPSS topics in order of importance to you as reading material in *Polio News*? (Mark with numbers 1 to 7 -- 1 for most important):

Board minutes	<input type="text"/>
Support groups contact list	<input type="text"/>
Editorial comment	<input type="text"/>
President's message	<input type="text"/>
Letters to the Editor	<input type="text"/>
Board comments on topical items	<input type="text"/>
Support groups news	<input type="text"/>

Is *Polio News* okay as it is or does it need changes?

Keep it as it is

Make these changes

Would you like to see more or less of the following topics? (mark plus or minus beside each item)

Disability services in NZ	<input type="text"/>
Computers and internet	<input type="text"/>
Overseas polio network news	<input type="text"/>
Wheelchair/scooter maintenance	<input type="text"/>
Household/personal mobility hints	<input type="text"/>

Do the following topics interest you (tick if yes)?

Accessible NZ travel	<input type="checkbox"/>
Accessible NZ accommodation	<input type="checkbox"/>
Accessible overseas travel	<input type="checkbox"/>

THANK YOU! Your answers to this survey will help us to make *Polio News* more interesting.
-- EDITOR.