

June's Iron Lung Guinness World Record

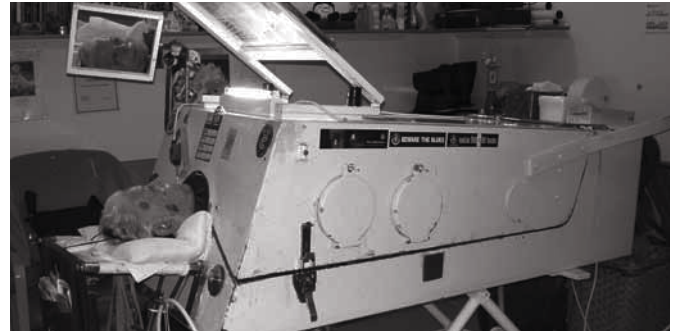
On Friday 2nd February, following an application by the Polio Network's Polio Advisory Committee, Peter Turner, CEO of ParaQuad Victoria joined with team members of AFL's Carlton Football Club to present a very proud June Middleton her Guinness World Record certificate. The wording on the Certificate read:

June Middleton of Melbourne, Victoria, Australia, has relied on an iron lung to keep her alive since contracting polio in April 1949. Ms June Middleton (b.4 May 1926) spends approximately 16 hours each day on the negative pressure respirator and has done so to date for over 57 years.

"I am delighted to have been invited to present this award", said Mr Turner. "Heading up an organisation which has the Polio Network as one of its key services, I have become extremely familiar and supportive of this important service to the community."

Carlton Captain, Anthony Koutoufides, assisted in the presentation of Ms Middleton's World Record certificate. "June has been a wonderful supporter of the Carlton Football Club for a long time; she has built some very strong friendships". In fact, June keeps a poster on the team on the inside lid of her iron lung stating that she "sleeps with the whole Carlton Football team every night".

Ms Middleton, 80, contracted polio in 1949 at the age of 23 and now spends 18 hours a day at Austin Hospital's Bowen



"I suppose it is amazing when you consider the doctors told my parents I wouldn't last 24 hours, and I'm still here 57 years later..."

Centre inside the machine which helps her breathe. "I suppose it is amazing when you consider the doctors told my parents I wouldn't last 24 hours, and I'm still here 57 years later," Ms Middleton said.

"June is one of approximately 70,000 Australians who between the 1930's and 1960's were paralysed by Polio", stated Mr Turner. "Most people recovered with varying levels of disability, going on to lead active lives. June, however is one of the few who has had to rely on an iron lung over the last 57 ½ years to keep her alive". This Guinness World Record may seem a dubious honour, but June still sees her life as a major achievement".

Also present at the Award presentation on the day were members of the Austin Hospital, where June currently lives, some of June's family members and closest friends, and representatives from the Polio Networks' Polio Advisory Committee, Barbara Watson and Michael Judson (pictured), who instigated the Award.

June hoped her record would spotlight polio and encourage parents to vaccinate their children. The presentation was shown on Channel 10, 9 and 7 news broadcasts (which can be seen on the Polio Network's website: www.polionetworkvic.asn.au/news-events), as well as printed articles in various newspapers including the Herald Sun, and e-news websites.



L-R: Barbara Watson, Mary-ann Liethof, June Middleton and Michael Judson

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PAC Meeting Dates 2007

- | | | |
|----------|----------|----------|
| • 30 Mar | • 29 Jun | • 28 Sep |
| • 27 Apr | • 27 Jul | • 26 Oct |
| • 25 May | • 31 Aug | • 30 Nov |

USEFUL PHONE NUMBERS

Polio Network Victoria:

- Direct Line 9418 0411
- Switchboard 9415 1200
- 1800 805 384

Polio Services Victoria 9288 3845

Breakdown Service (RACV) 131 111

Carers Association 1800 242 636

Centrelink - Disability 132 717

Centrelink - Aged 132 300

Disabled Motorists (Vic) 9386 0413

Emergency After Hours Service 1800 059 059

Emergency Wheelchair and Scooter

Independent Living Centre 9362 6111

1800 686 533

TADVIC

(Vic-wide custom designed equipment) 9853 8655

Victorian Aids and

Equipment Program 1800 783 783

From the Editor



Well here we are again, and it's March already! For those of you who still have gardens, hopefully we'll get a bit of rain soon...

*The main activities I have been occupied with so far this year have been to organise my **Polio Support Group visits** (page 12) and **Information Sessions** (page 3), as well as discussing ideas for **Polio Day 2007**. This year, Polio Day will be on Monday 22nd October to be held at the Darebin Arts & Entertainment Centre in Preston. Some of you may already know the venue from attending the Dr Marcia Falconer forum in May 2006. It has ample (free) parking on a flat surface and is close to main arteries and public transport. We have booked the whole facility (except the theatre), so should have more than enough room to move about – and it's all on the one level. More details to come in future editions of Polio Perspectives.*

*Sent out with the last edition was a brochure called **"The Late Effects of Poliomyelitis: Information for Health Professionals"**. This brochure appears to have been well received and many people contacted me for additional brochures. At the instigation of one 'patient', I even had a call from a medical clinic requesting brochures for their whole team! Please feel free to contact me on Ph: 9418 0411 or Email: polio@paraquad.asn.au if you would like a few more to share with your health practitioners.*

*I have been invited by our NZ counterpart, the **Post Polio Support Society of New Zealand Inc**, to attend and speak at their committee meeting in Wellington during the first week of March. Very exciting! I will be discussing how Polio Network Victoria operates, including comparisons with the other state networks. NZ, like all polio support networks, is reflecting on ways to keep their service relevant and vibrant. We may all be 'getting on', but there is a constant stream of polio survivors who are only just learning about post polio syndrome and need all the information the polio networks can provide. We must also consider the younger polio survivors who have migrated from countries where polio has only been eradicated in more recent times – or is still active.*

*Still on the subject, the Post-Polio Network (NSW) Inc is organising a 'think tank' scheduled for May entitled: **"Polio Australasia – Designing a Future"**. This will include polio network representatives from all states, as well as specialists such as Dr Stephen de Graaff and Jane Henderson from Polio Services Victoria. It should prove to be a very interesting and important conference with the aim of: Formulating strategies to ensure the continued operation of Post-Polio Networks across Australia and NZ; and Determining a National Plan to provide essential services to our members. Details will be provided in the Winter Edition of Polio Perspectives.*

*I'm determined that the **School Speakers Program** will progress this year, so for all of you who are still waiting for the call, it WILL happen . . .*

Last but not least, a big "THANK YOU" to all readers who sent in donations towards the production of Polio Perspectives, and I hope everyone continues to enjoy the newsletter throughout the year. Feedback and stories are always welcome.

I hope to meet up with you some time during the year – Mary-ann Liethof

Never let the future disturb you. You will meet it, if you have to, with the same weapons of reason which today arm you against the present.

Marcus Aurelius

Polio Perspectives welcomes articles of interest and reserves the right to edit or reject submissions as it sees fit. Published articles do not necessarily reflect the policies of the organisation. Any information in Polio Perspectives is not intended to be a substitute for professional medical advice.

Polio Network

2007 Information Sessions on the Late Effects of Polio

Mary-ann Liethof from the Polio Network will be travelling to several regional and metropolitan towns during 2007 to facilitate two hour information sessions on the Late Effects of Polio. These will all be run from 1.00pm to 3.00pm at various community facilities. If you would like to attend any of these sessions, contact Mary-ann directly on Ph: 03 9418 0411 or 1800 805 384.

WHERE	WHEN	WHERE	WHEN
Maryborough Maryborough Highland Society Inc 35 High Street	April Friday 13th	Seymour Community Services Building Seymour District Memorial Hospital, Bretonneux Street	July Tuesday 3rd
Melton Melton Community Health Centre Cnr High & Yuille Streets	June Friday 1st	Warragul West Gippsland Healthcare Group 34 Queen Street	July Day/date to be confirmed
Echuca Primary Care - Echuca Regional Health Leichardt Street	June Tuesday 26th	Torquay Torquay Senior Citizens Centre Inc 16 Price Street	October Thursday 11th



Polio Services Victoria (PSV) Clinics in 2007

St Vincent's Hospital Melbourne
41 Victoria Parade, Fitzroy
Ph: 03 9288 3845 / Email: psv@svhm.org.au

Regional

Ballarat	March 23rd
Traralgon	June 8th
Mildura	July 25th
Leongatha	September 26th
Warrnambool	November 28th

Metropolitan

Clinics are held on most Tuesday afternoons at St Vincent's Hospital Melbourne.

PSV Funding Submission

PSV has been seeking an increase in funding to match the demands of the service for several years now. A formal application was submitted to the PSV funding body, the Department of Human Services (DHS) in September 2005. This document outlined the growth in service provision. It reported statistics on the increased number of clients accessing the service.

It detailed the decreased age of new clients, who require more resources over a longer period of time; and the higher percentage of clients from a non-English speaking background, who again have greater needs from the service.

This submission was followed by several other documents throughout 2006. There were also many phone calls, emails and a couple of meetings with the DHS. PSV has not yet succeeded

in acquiring additional funding. However, we continue to lobby the DHS in getting the resources we need to meet your needs, in delivering a more timely and effective service for you.

PSV Service Provision

PSV has had the same staffing hours and numbers and the same funding (excluding an annual indexation increase) since 1999. This is difficult to manage when in 2006:

- PSV client numbers have grown from 579 to 1158 (a 100% increase).
- The mean age of new PSV clients has reduced from 71 to 43 years.
- The cost of equipment, such as orthoses and wheelchairs, has increased without an increase in the government funding of equipment.
- Staff salary & wages have increased over the past 7 years (at a greater percentage than indexation).
- There seems to be less knowledge among health professionals about polio in the community. This has increased the demands on PSV to provide education, and has made it more difficult to refer clients for management in the community, extending the waiting list for management at PSV.

PSV expect that waiting lists will continue to be a problem in 2007. PSV will attempt to manage the growing client numbers by referring clients when appropriate. This will mostly be for review management after comprehensive assessment by PSV, and for non-complex orthotic manufacture, therapy or equipment prescription.

Challenges Still Remain for the Global Polio Eradication Program:

A Summary of the Situation in 2006 and Looking Forward

by Dr Bruce Thorley
Head, Australian National Poliovirus Reference Laboratory

Polio is now endemic in only four countries: Afghanistan, India, Nigeria and Pakistan.

This is the lowest number of countries endemic for polio since the Global Polio Eradication Initiative was launched in 1988 when there were more than 350,000 cases in 125 countries.

The lowest number of polio cases recorded was in 2001, with 483 cases. Less than 2,000 cases were reported in both 2005 and 2006 (Table), which represents a great achievement but the ultimate goal of polio eradication has remained elusive.

India and Nigeria are the two countries with the majority of endemic polio cases and also the source of importations into countries previously declared polio-free. The large outbreaks due to imported polio in Indonesia and Yemen in 2005, have now been stopped, while the number of cases in Somalia has significantly decreased.

“This is not just about meeting a goal. It is about delivering a perpetual gift to every future generation of children to be born.”

In response to the continuing transmission of wild poliovirus, WHO has implemented targeted strategies for each of the four remaining endemic countries. In India this includes the use of monovalent oral polio vaccine type 1, which is reported to be twice as effective for immunisation against poliovirus type 1 compared to using the traditional Sabin oral trivalent vaccine. Poliovirus has three closely related serotypes referred to as types 1, 2 and 3. Wild poliovirus type 2 has probably been eradicated globally as it was last isolated in 1999. The majority of cases in India are caused by poliovirus type 1. In those areas where poliovirus type 3 is still endemic, monovalent oral polio vaccine to types 1 and 3 are used for vaccination.

The new Director-General of the World Health Organization, Dr Margaret Chan, took office on 4 January 2007. Dr Chan committed the organization to completing polio eradication and has invited all the major stakeholders to an urgent consultation in Geneva on February 27-28, to address the operational and



L-R: Bruce Thorley, Kerri Anne Brussen, Jason Roberts and Aishah Ibrahim, Victorian Infectious Diseases Reference Laboratory (VIDRL) team

financial challenges that the eradication program faces. This includes a global funding gap of US\$575 million for 2007-8. While polio eradication is technically feasible, Dr Chan spoke of the need to have political commitment from the four remaining endemic countries and the need to work with the donor community to provide the necessary resources. “Quite simply, we must succeed”, she said. “This is not just about meeting a goal. It is about delivering a perpetual gift to every future generation of children to be born.”

Source: WHO web site; <http://www.polioeradication.org/content/general/LatestNews200701.asp>

Global Case Count		
Cases of wild poliovirus worldwide as of week 6 February 2007		
	2006 = 1,968	2005 = 1,906
ENDEMIC COUNTRIES		
Nigeria	1,105	770
India	666	65
Afghanistan	31	7
Pakistan	40	27
IMPORTATIONS FROM ENDEMIC COUNTRIES		
Somalia	36	177
Namibia	19	0
Bangladesh	17	0
Ethiopia	17	22
Niger	11	10
Democratic Rep of Congo	12	0
Nepal	4	4
Indonesia	2	302
Yemen	1	478
Kenya	2	0
Angola	2	10
Cameroon	2	1
Chad	1	2

Source: WHO web site; <http://www.polioeradication.org/casecount.asp>

Pilot Study to Identify PPS Biomarker

Helping Each Other Help Others LEADERSHIP

by Nancy Baldwin Carter, Omaha, Nebraska

Reprinted from *Association Members Communiqué* (No. 7; February 2007), an e-newsletter from Post-Polio Health International (www.post-polio.org)

Q: "I read with enthusiasm that PHI awarded \$25,000 to the University of Arkansas for Medical Sciences to do a pilot study to determine if there is a unique biomarker (Tregs) in the immune system of individuals with post-polio syndrome. One member was less-enthusiastic because it was feared that if he/she did not have the biomarker the physicians would not treat them for PPS. This fear was fueled by the fact that it was so difficult to get the diagnosis of post-polio syndrome in the first place. Can you help resolve this fear?"

A: We've come a long way, baby! And what a switch! Isn't it refreshing to hear concerns from people who are worried that having a PPS diagnosis available will get in the way of appropriate medical treatment—when for years some of us were certain that NOT having a PPS diagnosis would end our chances to be properly cared for!

Indeed, there was a time when some of us seemed more concerned with having the initials "PPS" tacked onto our condition than we were with having an accurate diagnosis. Years ago some fought for those initials even when such a designation made it difficult to get disability, and perhaps impossible to get treatment. Were we truly looking for a solution?

Remember how it was in the beginning? For a while we didn't even have a name for the condition that needed a diagnosis. Should it be "Post - Polio Sequelae"? Or "Late Onset Polio Sequelae"? Or "Late Effects of Polio"? Or, well, any number of others that indicated that something was happening beyond polio that needed attention. In the end, the powers that be settled on post-polio syndrome, and for all these years we've received various degrees of help for PPS, even without a definitive method of diagnosis. We still rely pretty much on a diagnosis of exclusion.

In case anyone thinks we're at the end of the line here, and there's no longer a need to develop easy diagnosis, take a look at these estimated figures: Of 640,000 * polio survivors in the United States, 300,000 of them may already have PPS. Population-based studies show that anywhere from 20-78% of polio survivors complain of new neuromuscular symptoms often attributed to PPS. Worldwide, as many as twenty million polio survivors live with, or are at risk for acquiring, PPS. And acute poliomyelitis continues to this day in certain parts of the world. It's going to be a long time before there won't be any more polio survivors seeking a diagnosis for PPS.

Small preliminary studies already indicate that excessive numbers of regulatory T cells (Tregs) show up in people with

PPS, but not in healthy individuals who were vaccinated with oral (live) polio vaccine, and that Tregs from some of those with PPS do not function normally. If this situation occurs in a larger study (this time including those with PPS, those with polio but no PPS, and those who are healthy), then this could mean these Tregs are a biomarker pointing to PPS. That could be cause for a PPS diagnosis.

Would this mean that polio survivors without those extra Tregs will not receive treatment for PPS? Possibly. This is all speculative, of course, but I can't imagine why people without PPS would be treated for PPS – or why they would want to be. At the same time, I'm not exactly sure what that means. We all had polio, and surely we would be treated for our polio problems, commensurate with their severity. Certainly no doctor would insist on seeing further deterioration through PPS before treating an imminent difficulty.

Leaders of polio groups can find a wonderful opportunity for discussion in this topic. What do your members have to say about some of these questions?

- Can certain polio survivors who may never develop PPS still have significant physical difficulties? What if these problems require careful attention or even necessitate procedures such as major surgery, for example? Would any doctor refuse to address these situations adequately?
- Isn't "the late effects of polio" a term that defines all of us, while "post-polio syndrome" indicates that some of us have late effects that go further than our initial polio? Do we all fall at a slightly different place in this continuum? What does this have to do with diagnosing PPS?
- How do we explain the importance of this research? If this hypothesis regarding regulatory T cells in PPS immune systems proves significant, is it possible that this could lead to even greater discoveries, perhaps in the area of PPS treatment?

Years ago we had a quadriplegic member on our board of directors at Nebraska Polio Survivors Association who used to joke he wasn't worried about getting PPS since he had nothing more to lose. Whether he was right or wrong was irrelevant. It didn't matter where he landed on the "late effects" progression. We were glad he was there, lending his considerable expertise, helping our organization bring valid information to as many as possible in the polio and medical communities, and demonstrating the importance of reaching out. It was a good mission.

* Joan L. Headley tells me that PHI is investigating this number as well as the age distribution of polio survivors. We await the analysis and the numbers.

Nancy Baldwin Carter and Joan L. Headley are co-authors of the chapter "Support Groups: Keeping Them Active and Useful" in Lauro Halstead, MD's new book *Managing Post-Polio: A Guide to Living and Aging Well With Post-Polio Syndrome*. The book is now available online at: www.nrhrehab.org

Did you miss the press release about PHI's fourth research award? Go to: www.post-polio.org/resrch.html - Post-Polio Health International Awards Research Grant to University of Arkansas Team (pdf)

Noticeboard

Increase in KAFO Funding

Many readers signed a petition in 2005 generated by Tricia Malowney of the Eastern Polio Support Group Inc requesting an increase in Knee-Ankle-Foot orthotics (KAFO) funding. The Dept of Human Services has since completed a review of the subsidy level available for KAFO's through the Aids & Equipment Program and has issued the following statement.

The Victorian Government has provided additional recurrent funding of \$93,500 to the Aids and Equipment Program (A&EP) for a new subsidy level for Knee-Ankle-Foot Orthoses (KAFOs). The current subsidy of \$1,200 will be replaced by the new subsidy of \$2,200 per item per year. It is anticipated the new subsidy level will fully fund the basic metal KAFO and significantly reduce the contribution required by clients for other types of KAFOs.

This is a great victory for many the polio survivors who require KAFO's and just goes to show what can be achieved when we work as a 'network'!

Ed

Senior Citizen of the Year

AUSTRALIA DAY AWARDS: CITY OF GREATER DANDENONG
STAR NEWS – 24TH JANUARY 2007



Lyn Bates has fought a personal battle with polio for more than 50 years. But it is her public battle to have the once-prominent disease recognised in case it once again returns to haunt future generations which has earned her the award.

At age six, Ms Bates was diagnosed with the debilitating disease and now battles against the painful effects of Post Polio Syndrome. The virus has also confined Ms Bates to a wheelchair.

She is president of the South Eastern Region Polio Support Group, an advocacy organisation appealing to young mothers to ensure their children are vaccinated against the disease.

Ms Bates is also recognised for her work promoting respect and equity for people with disabilities.

Irish Email Pal

I am a 55 yo polio survivor living in Ireland, and a member of a local polio support group. I was looking up your web site and wondered whether any of your members would be interested in getting in contact with me over the internet to share topics of mutual interest.

My email address is:
VScully01@eircom.net
– Vincent Scully

Away With the Birds

THE EXPLOITS OF PAULINE CORRIGAN AS REPORTED BY HUSBAND, TOM



After hearing a report from his registrar regarding her concern over a patients' latest past time, Dr Stephen de Graaff's reply was, "That's OK, Pauline can continue learning to fly airplanes, as long as she doesn't crash. It's better she does that than continue to turn out to fires driving the fire truck."

Further proof you can't keep a post polio sufferer down! With the Air Show interests and a few of our friends' interest in flying Jabiru ultra light aircraft, I gave Pauline a training introductory flight voucher for Christmas. She went on this flight and found she liked the idea of flying. However, the set up in the aircraft upset her leg greatly so she expressed her concern about this and the instructor said he could put adaptors on the pedals to help, as well as adjusting the seating with cushions. So next flight they tried this and were happy with the result. Pauline has completed two training flights now. On the second, she landed the airplane under instruction, which is an achievement.

Pauline is continuing with her flying lessons. Maybe we should be calling her "Biggles". Ed

Safety in the Shower



Margaret Griffiths, convener of Bairnsdale Polio Support Group, has found a wonderful, 'safe' mat to stand on in the shower. "The reason why I think they are so good is that they are much safer to stand on,

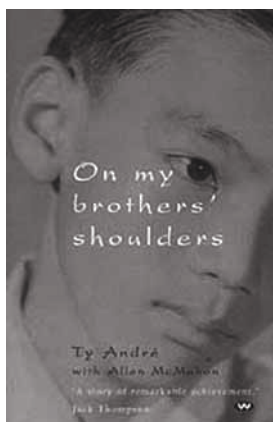
no slippery surface. The soap and shampoo does not sit on top, it goes through the mat. You feel more secure. Merle (fellow group member) felt the same way, she had slipped on an 'ordinary' shower mat."

The difference with these mats are the 'feathery' plastic 'spikes' that cluster around holes which allow for draining. The mat also has suction cups that fasten it to the shower base. Margaret's mat, bought at Bunnings, was called the "Choocha Mat, Massage Bath Mat", made in Israel by Lotemplast. Unfortunately, after an extensive search of Bunnings stores and the Lotemplast website, we were unable to track down this brand. However, I have found the same type of mat with the intriguing name of "Full Funny Bath Mat – Spa / Bath Mat Fresh Taste" in a '\$2.00-type' shop in Bulleen Plaza for \$11.95. I can only assume that it is not the only stockist, so start hunting!

Ed

“On My Brothers’ Shoulders”

by Ty Andrè with Allen McMahon



*Review by Suzanne Ryan-Evers,
Communication Manager,
Paraquad Victoria*

Just had to let you all know about a fantastic book that I read over the Summer holidays. It's an autobiography written by Ty Andrè, one of ParaQuad's clients who has Post Polio Syndrome.

I met Ty last year (2006) when I was doing the photo shoot for our Annual Report. What an amazing man! He has lived an incredible life to date.

The book is a detailed account of his life, from the time he was found in a woven basket floating down the Mekong River in Vietnam through to his arrival here in Australia. He tells of so many adventures, or should I say 'close calls', and of his transforming relationship with the man who saved him from certain death.

If you like a good read, this one is truly inspirational. What's more, thanks to Ty, there's two copies of the book, and the video he subsequently made, available for loan in the ParaQuad library – Ph: 9415 1200.

*To buy: RRP \$19.95 Biography/Autobiography/True Stories
APN9781862543782 Wakefield Press*

Post Polio Syndrome: The Australian Experience



Have you got your copy yet?

In addition to assisting with the management of PPS symptoms, many people have found the film invaluable in helping their families and friends understand the issues they are dealing with. DVD Chapter profiles can be seen on the Polio Network website: polionetworkvic.asn.au or contact Mary-ann on Ph 9418 0411 for further information.

The DVD and video are available from the Polio Network, 208 Wellington St., Collingwood, Vic., 3066, Phone (03) 9418 0411 or email polio@paraquad.asn.au. Once an order is placed, an invoice will be sent with the product which can be paid by credit card or cheque made out to ParaQuad Victoria. The cost is \$15 plus \$2.45 postage (total = \$17.45). Please specify whether you want the DVD or video.

ParaQuad Victoria's Library

Open 9am – 5pm, Monday to Friday. Phone (03) 9415 1200
Located at Level 3, 145 Smith Street, Collingwood

ParaQuad Victoria has a library based in its Smith Street office building. The library holds a range of books, videos, journals and other print materials for and about people with disabilities, including spinal cord injury and on all of the subjects below. It also maintains a collection of local and international materials on polio and its effects.

We welcome visitors to our library and encourage people to make use of this valuable resource. Please ring first to ensure a staff member is available.

Library resources are available for loan to members and their families. Others are welcome to use the library for research on the premises. Anyone working or studying in rehabilitation, care or education of people with disabilities may borrow by paying our membership fee and producing identification.

Subjects covered include:

- Access/building/outdoor/design
- Accommodation/independent living
- Advocacy/law/social justice/politics
- Aids/equipment/technology
- Biographies
- Community services/pensions
- Disabilities/diseases/disorders
- Travel/holidays/transport
- Social issues
- Education
- Employment
- Health
- Polio
- Relationships/psychology
- Recreation/leisure
- Sexuality
- Spinal Cord Injury

Donating to the 'Special Purpose Post Polio Account'

In June 2005, the Post Polio Foundation (PPF) transferred its funds to ParaQuad Victoria along with specific conditions for their use. The Guidelines specify that, "The aim of the fund is to finance the development of educational material and to conduct at least one post polio educational event per annum. Should larger sums of money become available (e.g. bequests), it would be desirable to be able to move beyond education to other forms of support for people with post polio once the educational activities have been undertaken each year."

Anyone interested in making a donation or bequest to be used specifically for post-polio related activities will need to specify that it go to ParaQuad Victoria's 'Special Purpose Post Polio Account'.

For further information, please contact the Polio Community Officer on Ph: 9418 0411.

Polio Network Website

The Polio Network has a new website which is worth having a look next time you're 'surfing the net': www.polionetworkvic.asn.au

Do you have an email address?

If you would like to receive Polio Perspectives electronically instead of through the post, please email me at polio@paraquad.asn.au



T'N'T: Tips and Techniques for Polio Survivors

by Dr Richard L. Bruno

Note: This column is for information purposes only and is not intended as a substitute for professional medical advice.

Q: Recently I had a fever with muscle and chest pain. The only abnormal blood tests showed high C-reactive protein and high creatine kinase. My blood pressure and cholesterol are normal, I have never smoked, and I'm thin. Because of the chest pain I had an angiogram, which was normal. Could high CRP and high CK be related to PPS?

A: C-reactive protein is a blood marker for inflammation somewhere in the body. High CRP can be seen with type 2 diabetes, autoimmune diseases and cancers. Could inflammation somewhere in your body, as indicated by your elevated CRP, be related to PPS? Fifty consecutive patients evaluated at The Post-Polio Institute had CRP measured. The patients were on average 59 years old and 55% were women. Thirteen percent had an elevated CRP, 66% of whom were men. CRP was on average nearly three times the normal value. However, there was no significant difference between those with high and normal CRP on self-ratings of daily fatigue, difficulty with self-care or ability to perform activities inside or outside of the home. So, there is no evidence that elevated CRP or inflammation is related to PPS, either to post-polio fatigue or difficulty in functioning.

there is no evidence that elevated CRP or inflammation is related to PPS, either to post-polio fatigue or difficulty in functioning.

Recent studies have found that elevated CRP is related to having a heart attack or stroke. The theory is that a bacterial or viral infection (although definitely not a poliovirus infection) somehow inflames arteries and causes them to clog. Our 1985 National Survey found no more heart disease or high blood pressure in polio survivors than in the general population. But two studies found that 5% more male post-polio patients had abnormally elevated cholesterol as compared to the general population. In one of the studies, only 33% of those with high cholesterol had been given a cholesterol screening test by their doctor and not even 25% were on cholesterol-lowering medications, like the statin drugs such as Lipitor, Pravachol and Zocor. This is not good, since reducing cholesterol reduces heart

attack risk. What's more, research has shown that taking statins to reduce cholesterol can also lower CRP and may thereby increase survival even after having a first heart attack.

Statin drugs provide a connection between CRP and CK--in polio survivors. CK is an enzyme released when muscle is damaged. One half of one percent of anyone taking a statin develops muscle breakdown, which causes muscle pain (especially in the calves), muscle weakness and an increase in CK. Even without muscle breakdown or an elevated CK, some polio survivors report muscle pain or weakness when taking a statin, usually one of the older statins like Lipitor. And polio survivors can have an elevated CK without taking a statin. Two studies found that 40% of polio survivors had abnormally elevated CK, with men having significantly higher CK than did women. In one study, CK increased with the number of steps polio survivors walked in a day. In our fifty Post-Polio Institute patients, 21% had abnormally elevated CK levels (on average about 33% higher than normal) with men also having higher CK than did women. But, as with CRP, there was no significant difference between those with high and normal CK on self-ratings of daily fatigue, difficulty with self-care or the ability to perform activities inside or outside of the home. However, an elevated CK may mean that polio survivors are making their muscles work too hard and are causing them to break down.

So, neither CRP nor CK is related to fatigue or loss of functional abilities in polio survivors. However, all polio survivors need to have their cholesterol and CRP measured to assess heart disease risk. And since an elevated CK indicates muscle breakdown, either from taking a statin or from muscle overuse, polio survivors should have CK measured before taking a statin. If you are worried about possible muscle weakness or breakdown with the statins, or the newer cholesterol-lowering drugs like Zetia and Vytorin, ask your doctor about using older medications like slow-acting niacin or bile acid sequestrants. Besides medication, polio survivors need to eat high fiber foods, reduce saturated fat, treat high blood pressure and stop smoking to keep their tickers ticking. •

*Dr. Richard Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center. His new e-Book, *How to STOP Being Vampire Bait: Your Personal Stress Annihilation Program*, is now available through PostPoliInfo@aol.com*

A Positive Polio

A positive polio – for crying out loud, what is this woman on about? 'A positive POLIO! My children believe I am crazy, my husband KNOWS it, and I am beginning to believe it myself.

I have always been mindful of my abilities and lack thereof. Having contracted polio in March 1955, age 18 months, and probably one of the last in Australia to contract the disease prior to the commencement of a massive immunization program which commenced in March 1956, and now at age 53, I look back on what I consider to be a 'positive polio' experience. In October 2005 I flew to Melbourne to be at Polio Day 2005 and must admit the motivation for my attendance was guest speaker on the day, Betty Fussell. That I was to rate a mention in Miss Fussell's address whilst referring to the visit of Princess Alexandra to the Lady Duggan home in 1959 (at the time I was 6 years old) almost floored me. That I am an up front enough type person to have stood up and responded at the end of her presentation led me to an even greater surprise when, as we broke for lunch, a lady in front of me turned and said, "Janet, Judy Lee would like to speak to you." (There go the goose bumps again.) As the goose bumps began to subside, my first thought is, "Oh, I wish Mum was here." Sadly, Mum (Jean) wasn't here, having passed away just three years earlier aged 84.

And here I digress: March 1955, and Jean, my Mum, a trained nurse, and district nurse for quite a large area surrounding Beachport South Australia (the home of SAFCOL), had been keeping an eye on me as I had been unwell with cold type symptoms for a few days. With the stiffening of my legs, she knew in her mind that Polio had come to call and with this the family support network, which continues to this day, sprang into motion. Dr Peter Salt in Millicent, some 35 km from Beachport, advised Mum and Dad (Fred) to head to either Adelaide or Melbourne, "Now!". Millicent being approximately half way between the two major cities, the decision to head for Melbourne was an easy one as aunt and uncle, Mildred and Jack Fairbridge ran the post office at Dunkeld, some 200 km away, a good spot to have a break and also to swap cars, our old for Mildred and Jack's new vehicle. At the swapping point, Jean insisted that all involved stay away from me (she didn't want to run the risk of anyone else becoming ill with what she now knew in her own mind to be Poliomyelitis).

On arrival in Melbourne it was straight to the Fairfield Infectious Diseases hospital. The next few years (how much can a child between 18 months and 4 years of age remember) are somewhat hazy. Hindsight, as they say, is a wonderful thing and I only wish now I had quizzed Mum more on these years. Mum travelled from Beachport to Melbourne on a regular basis with me in a splint set up on a "Fred made" frame in the car so I could see what was going on along the way. I always thought



Christmas 1957 at Fairfield Hospital: Jan with Lou Topano & Bert Newton

... I only wish now I had quizzed Mum more on these years ...

Dad should have patented the name "Fred made" for there was nothing my Dad could not organize to make my life as comfortable as possible. The trips were made in order that I could receive ongoing treatment and monitoring by the wonderful doctors and physiotherapists at Fairfield. And this brings me back to Judy Lee.

Judy was my first physiotherapist at Fairfield and we featured together in an article published in the Melbourne Sun entitled, "The Wide-Eyed Wonder of Learning to Walk: Little Janet Edwards, aged 4, is learning to walk again". Well, learn to walk again, I did – and with the wonderful support of my family, my physiotherapists, particularly Judy Lee at Fairfield and Betty Fussell at the Lady Duggan Home, that walk still goes on. I have had an amazing walk in life and the more so I believe because of the positive attitude encouraged by all of my supporters.

This is the beginning and I hope, in the not too distant future, to have put together the whole wonderful story. •

Jan Williams (nee Janet Edwards)

Jan would like to hear from anyone who was at Fairfield and Lady Duggan from 1955 onwards stating, "I have the most wonderful memories of particularly Lady Duggan from about 1959 on and would very much like to contact others who were there at that time to assist in the completion of what might be a book, or what might just be a catalogue of memories of my years with polio." Jan can be contacted by email on: rayjanwilly@optusnet.com.au

Ed

Legends of East Gippsland: Louis Pruscino

The following story is reprinted with kind permission and courtesy of East Gippsland News – first printed in the Bairnsdale Advertiser (Abridged Version)

After a lifetime of coping with a disability, Louis Pruscino remains philosophical about the card he was dealt at the tender age of 18 months. "You accept what happens and move on, I'm still luckier than a lot of people", says Louis, who was born in Bairnsdale in 1940 and contracted polio at the height of the Australian epidemic. "I woke up crying with a fever in the night unable to support my leg." He says people are affected differently because where the virus rests in the spinal cord determines what part of the body is affected, but treatment at any level was prolonged and arduous and at the time meant years in hospital.

Lou's story reveals just how much attitudes towards people with disabilities have changed in the last 50-60 years, and just how much a determined youngster can achieve despite the odds. His parents, Antonio and Filomena Pruscino, always treated him equally with the other children in this close and industrious family. They were from Sano Lupo, Italy, 100km from Naples. In 1938 Antonio was sponsored by his brother Pasquale who had lived in Wy Yung for several years. "Dad came out on a merchant ship and was sick every day, he swore he'd never go back." His brother had come out several years earlier and worked as a labourer. "Dad did labouring, truck driving and worked with the Country Roads Board. About 18 months later he brought out my mother and my elder brother, Giuseppe, who was two years of age – they came on the last ship leaving Italy before the war broke out."

They were still living in Wy Yung when Lou contracted polio. He was rushed to Sale Hospital where he spent a couple of years. A it was wartime his dad was interned at Maffra, working on the sugar beet, and had to walk or borrow a bike to visit Lou at Sale – it was almost impossible for his mother to see him. Then he was sent to the Austin Hospital in Melbourne – where he could hear the trains – and was always telling people he would be a train driver. "I was about seven when I finally came home and the family was renting a small house on the same property as the Exchange house in Lucknow – years later the family bought the property and started the store." By then there were three more siblings, Assunta, Albert and Lena.

I came home with two callipers and two walking sticks as well as a brace for the spine as I had curvature of the spine. Therapy was severe – **at night he would be tucked into a splint – spreadeagled and unable to move with his hands and feet tied.** He had to walk to school at Lucknow and one evening Chas Yizzard, the Peugeot agent who owned the business behind the servo, saw him walking and called in to see his parents, offering to help.

"Eight to 10 years earlier Chas had been bedridden with no hope of walking again, but after visiting an osteopath was back in action after six months. So from his own heart he took me and another young man from Paynesville, to Melbourne, to visit the

American osteopath Alice Virginia Farnam, who worked from a private residence in Brighton at weekends and had a practice in Collins Street.

She would manipulate my spine and said we could throw away the brace –the spine needed to be re-educated. Also the left leg calliper should only be used on alternate days. She said it was weakening the leg. The right could not be helped - but her main concern was for the health of the spine. I saw her for 18 months then she said she couldn't do any more. She did this at no charge.

During this time the polio specialist from the Department of Health would visit the Bairnsdale Hospital once a month. He said if I continued going to the osteopath he would have nothing to do with me – despite the obvious improvement. My local doctor would also have nothing to do with me and referred me to another doctor.

We moved back to Wy Yung – next to the pub – there was no water, no electricity. The school bus passed by but I couldn't be picked up because I was under the three mile limit. Here I am losing school – so as a last resort dad saw Sir Albert Lind one Sunday. By the Wednesday wed got a call that the bus would pick me up on Thursday but because the route went to the high school I had to go to state school 754 to do grade six, though brothers and sisters went to St Mary's.

When I was at Lucknow, because I was growing, every six months the calliper and brace would need replacement – needing four or five weeks at Yooralla. I'd stay at the Deva Hostel in Acland Street, St Kilda – home for 20 country children and adults. A Red Cross driver and vehicle would take me to Yooralla and back each day – I have great admiration for what Red Cross do for us.

[As an adult] Lou has been proactive on issues to do with disability. Polio sufferers, with varying degrees of problems, meet in Bairnsdale to discuss issues. Lou says a main problem for all who suffered polio is PPS (post polio syndrome) because a part of the body has been affected for a long time other parts have had to work harder and so they are all wearing out much earlier. "Until the last two or three years I only needed one walking stick – now its back to two because the better leg can collapse – and there are the shoulders which have borne the weight so long. When we meet we discuss these problems - people come and talk to us – we thought it was old age - but it's PPS. •



*The full version of Lou's story can be seen on the Polio Network website:
www.polionetworkvic.asn.au/polio-stories*

Polio Advisory Committee Election

Application Form 2007 – 2009

The **Polio Advisory Committee (PAC)** is currently seeking applications from people interested in discussing issues, contributing ideas, and suggesting actions for the Polio Community Officer to follow through on. Four new positions on the PAC will be taken up in July 2007 and cease at the end of June 2009.

The PAC meets at ParaQuad Victoria offices, 208 Wellington Street, Collingwood on the last Friday of every month (except Dec), unless otherwise agreed by members, and comprises a representative group of rural and metropolitan people who can commit to the following:

Roles

The role of the PAC is to:

- advise PQV Board via the CEO of PQV through the Polio Community Officer on issues of relevance to people who have had polio;
- assist the Polio Community Officer in developing action plans;
- confer with the Polio Community Officer when matters need to be discussed and/or clarified
- provide assistance and support at Polio Network Victoria events and seminars
- be consulted in the planning stages of Polio Network Victoria's ongoing Strategic Plans and Budgets

The role of individual members of the PAC is to:

- bring issues relevant to members of Polio Network Victoria to the attention of the Polio Community Officer and/or PAC for consideration and action

- represent members of Polio Network Victoria when invited to participate in ParaQuad Victoria's planning days and other activities, which include client/customer input

Responsibilities

Each member of the PAC:

- **must be a current financial member of ParaQuad Victoria**
- will abide by the PAC Guidelines
- will bring to the PAC issues raised by members of Polio Network Victoria for discussion and/or clarification
- will actively and positively promote activities, events and services of Polio Network Victoria and ParaQuad Victoria among members of Polio Network Victoria and the wider community

Ballot Papers detailing applicant profiles will be included in the Winter Edition of Polio Perspectives in the first week of June. All Victorian Polio survivors can vote for their preferred candidates and will need to return Ballot Papers to the Polio Network by 5 pm on Friday 22nd June 2007. The ballot paper will also be posted on the web site and voting by email will be available.

If you have any queries regarding the PAC please contact either Gordon McKinnon, PAC Chairperson on Ph: 5565 8660, or Mary-ann Liethof, Polio Community Officer at ParaQuad on Ph: 9418 0411 / Email: polio@paraquad.asn.au. To give you an idea of PAC activities, Guidelines and Minutes can be found on the Polio Network's website: www.polionetworkvic.asn.au/PAC.

Please return completed forms by no later than 5pm on Friday 30th March 2007 to:

PAC Applications, Polio Network Victoria
208 Wellington Street, Collingwood Vic 3066

Applicant details

Name: _____ (PLEASE PRINT)

Address: _____

Phone/s: _____ Email: _____

Interest: Please attach a brief profile of yourself and your interest in joining the PAC. Also include a current photo (returnable) or email a digital photo for use in the Ballot Papers.

Category: (tick any categories as appropriate)

Rural*

Metro

Polio Support Group Member

Independent

*Rural reps can nominate a deputy person with whom they can share attendance at monthly meetings

(not a Support Group Member)

Return To:

PAC Applications, Polio Network Victoria, 208 Wellington Street, Collingwood Vic 3066 Email: polio@paraquad.asn.au

Polio Support Group Contacts

Ballarat Post Polio Support Group Inc

Meeting: 1st Wed in February, then bi-monthly
Cliff Sewell ph: 5339 5364
Ruth Grose ph: 5332 4755
email: n_grose@vic.australis.com.au

Bairnsdale Post Polio Support Group

Meeting: 1st Tue in April, then bi-monthly
Margaret Griffiths ph: 5156 7646
email: d-mgriffiths@datafast.net.au

Bendigo Post Polio Support Group

Meeting: 3rd Sat in February, then bi-monthly
Bob & Dawn Colbourne ph: 5443 8161

Eastern Region PSG Inc (Box Hill)

Meeting: 3rd Sat of every month
Betty O'Brien ph: 9898 8377
Carol Membrey ph: 9887 4701
email: jcmembrey@optusnet.com.au

Geelong Polio Support Group

Meeting: 1st Mon of every month
Marion Kosseck ph: 5243 8848
Neil Winter ph: 5241 9591
email: timg@bigpond.com

Hamilton Post Polio Support Group

Not currently meeting
Jan Street ph: 5572 3572

Hume Polio Self Help Group (Wangaratta)

Meeting: 2nd Saturday of every month
Margaret Goodman ph: 5752 1347
Harry Wilkinson ph: 5722 1472
email: glendaharry@netc.net.au

Mornington Peninsula Post Polio Support Group

Meeting: 2nd Sat of every month
Dennis & Deidre Lloyd ph: 5974 3495
email: ddllloyd@aapt.net.au

Northern Region Post Polio Support Group Inc (Coburg)

Meeting: 1st Saturday of every month
Rosslyn Pickhaver ph: 9306 9018
Jo McKenna ph: 9308 8440
email: rosslynp@tadaust.org.au

North West Post Polio Support Group (Mildura)

Ring Group Contact
Betty Halpin ph: 5023 2528

Sale Polio Support Group

Meeting: 1st Fri in February, then bi-monthly
Kathy Glover ph: 5144 3443
email: bastian@dcsi.net.au

Shepparton Post Polio Support Group

Meeting: Quarterly – Ring Group Contact
Rhonda White ph: 5832 3100
email: Rhonda.White@gvhealth.org.au

South Eastern Region Polio Support Group (Springvale)

Meeting: 2nd Saturday of every month
Lyn Bates ph: 9546 5497
email: lyn_bates@bigpond.com

Swan Hill Post Polio Support Group

Ring Group Contact
Pat Dillon ph: 5032 1633

Traralgon Post Polio Support Group

Meeting: 3rd Thur in February, then bi-monthly
Pauline Corrigan ph: 5174 6904
email: pcorrigan@vic.australis.com.au

Warrnambool Polio Support Group

Meeting: 4th Tuesday of every month
Bill Hill-Peters ph: 5561 3980
Anne Clapham ph: 5562 5685
email: demar@bigpond.net.au

Western Region Polio Support Group

Not currently meeting
Maree Jongkryg ph: 9743 1273
email: beau.1@optusnet.com.au

Wimmera Polio Support Group (Horsham)

Meeting: 1st Sat in Mar, then quarterly
Gordon Reynolds ph: 5382 7303

Wonthaggi Post Polio Support Group

Meeting: 2nd Mon in Feb, then bi-monthly
Thelma Dowson ph: 5672 1148
Heather Wallace ph: 5672 3532

Yarra Ranges Polio Support Group (Ferntree Gully)

Meeting: 2nd Saturday of every month
Joan Smith ph: 9756 6383
Marlene Wookey ph: 9758 2232
email: joansgra@tpg.com.au

Eastern PSG Inc celebrates 15th Anniversary

The Eastern Polio Support Group Inc celebrated their 15th Anniversary on Saturday 17/2/07. The anniversary was attended by 28 members and 11 guests, including members from the Northern and Yarra Ranges Polio Support Groups and the Polio Network. It was wonderful to see so many of the foundation members in attendance who took the opportunity to catch up with old and new members, and to find names on the Polio Roll Call display. Cake cutting honours were given to Beth Brodribb, who is a Life Member of the group, in recognition of her hard work in helping to establish the group, and her dedication to ensuring that Victorian Polios have access to the services that we need.



L-R: back – Marj Canning, Rae Corran, Judith & Ron Bell / middle – Margaret Bennett and Betty O'Brien / front – Marj Bailey and Beth Brodribb

2007 Polio Network Support Group Visits

Mary-ann Liethof from the Polio Network will be visiting the following Polio Support Groups during the year. If you would like to attend one of these meetings, please ring the Group Contact listed above. New (and old) members will always be made welcome.

1. Bairnsdale	Tuesday 6th Feb	1.30
2. Eastern (Box Hill)	Saturday 17th Feb	1.30 (15th B'Day)
3. Yarra Ranges (Ferntree Gully)	Monday 12th Feb	1.30
4. Mornington Peninsula	Saturday 10th Mar	11.00
5. Wonthaggi	Monday 2nd Apr	2.00
6. Ballarat	Wednesday 4th Apr	12.00 for lunch
7. Bendigo	Saturday 14th Apr	1.00
8. Geelong	Monday 7th May	11.00
9. Hume (Wangaratta)	Saturday 12th May	1.30
10. Northern (Coburg)	Saturday 2nd Jun	1.30
11. Shepparton	Wednesday 6th Jun	12.30 for lunch (10th B'Day)
12. Traralgon	Thursday 21st Jun	1.00
13. South Eastern (Springvale)	Saturday 14th Jul	1.30
14. Warrnambool	Tuesday 24th Jul	12.30 for lunch
15. Sale	Friday 3rd Aug	1.00
16. Eastern (Box Hill)	Saturday 18th Aug	1.30
17. Swan Hill	Wednesday 15th Aug	12.30 for lunch
18. Wimmera (Horsham)	Saturday 1st Sep	1.00
19. North West (Mildura)	Saturday	12.00 for lunch (TBC after March meeting)
20. Southern Grampians (Hamilton)	(in recess)	
21. Western Region (Deer Park)	(in recess)	