

Polio Network Victoria

# Polio Perspectives

Vol 21 No 2 Winter 2009



**clockwise from back** Mary-ann Liethof, Liz Telford, Suzie – Historic Pools Guide, Fran Henke, Shirley Glance and John Tierney

## Living with Polio in the 21st Century conference

**In April 2009, Polio Survivors gathered at Roosevelt Warm Springs in Georgia for Post-Polio Health International's 10th International Conference: Living with Polio in the 21st Century ([www.post-polio.org](http://www.post-polio.org)).**

**The Conference** was preceded by a four day Retreat at 'Camp Dream', also located within the grounds. Both activities were attended by Mary-ann Liethof, Polio Community Officer (thanks to a grant from the Harold Mitchell Foundation); Liz Telford, Polio Advisory Committee

Member; Shirley Glance, Bayside Post Polio Support Group Convener; and Fran Henke, Mornington Peninsula Post Polio Support Group Member. Other Australian representatives included Dr John Tierney, a lobbyist and polio survivor from New South Wales; Dr Nigel

Quondoc, a Rehabilitation Specialist from South Australia; and Dr Margaret Peel, a polio survivor from Brisbane.

Shirley, Liz and Fran have all provided their impressions of the experience in this edition. – Ed

### Shirley Glance

Bayside Post Polio Support Group Convener

Someone once told me that if you come away with one thing you learnt from a conference, you have learnt a lot. Well I have come away with many things, which I will tell you about shortly.

When Mary-ann, Fran, Liz and I arrived at Warm Springs we acquainted ourselves with the surrounds and did a little sight seeing. The next day we registered for Camp Dream, which was attended by 62 participants. The setting was absolutely magnificent, overlooking a lake. What struck me was the serenity – it was as warm and welcoming as the name suggests. We were then allocated our accommodation

which consisted of two lodges – Callaway and Linear – ten rooms per lodge, each with four single beds.

When I first entered the lodge, I became quite upset. It reminded me of when I was in hospital, which was not a very comforting thought. But this was soon banished by the wonderful people at Callaway lodge. There were at least five couples in our lodge. I was overwhelmed by this and still marvel at the support and care the spouses provided throughout the whole time,

both at the Wellness Retreat and the Conference. It made me think about what our partners



### Inside

**Living with Polio**  
in the 21st Century



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is published quarterly by  
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## POLIO NETWORK VICTORIA

### Polio Community Officer

Mary-ann Liethof – 9418 0411

## POLIO ADVISORY COMMITTEE

### Chairperson

Michael Judson – 0412 302 997

(until end June)

### Members

Jill Burn – 9499 4015

Margaret Cooper – 9773 2437

(until end June)

Geoff Dean – 5662 2643

Jo McKenna – 9308 8440

Gordon McKinnon – 5565 8660

Liz Telford – 9489 8328

Peter Willcocks – 9578 5953

## PAC MEETING DATES 2009

• June 26 • July 31 • August 28

• September 25 • October 30

• November 27

## USEFUL PHONE NUMBERS

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 AH Service – 1800 059 059

Emergency Wheelchair and

Scooter – 9362 6111

Independent Living Centre

– 1800 686 533

Melbourne Mobility Centre

– 1800 735 266

TADVIC – 9853 8655

Victorian Aids and Equipment

Program – 1800 783 783

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.



## From the Editor

editor Mary-ann Liethof

As you read though other articles in this edition, you will see that **Roosevelt Warm Springs** was an amazing place to visit, especially with so many polio survivors sharing their memories and experiences of time spent rehabilitating there. An unforgettable, once in a lifetime opportunity that I'm glad I could share with my wonderful travelling companions Shirley Glance, Fran Henke and Liz Telford. As polio survivors, the perspective they provided me with made the experience all the more profound. I think our enthusiastic Australian presence will also be remembered by our new American and Canadian friends in the wider polio community. Now we will just have to see what we can do about running Retreats in Australia.

Unfortunately, we have just had news that a \$200,000 **Polio Australia** proposal to the Dept. of Health and Ageing to run six retreats across Australia as part of 'Chronic Disease Self-management/Lifestyle and Risk Modifications' was unsuccessful. So, back to the drawing board for funding options... We all know it's difficult to find funding in this current economic climate. However, every state Polio Network believes it is imperative to get Polio Australia up and running so it can concentrate on facilitating projects like the proposed Wellness Retreats, as well as lobbying at a national level on issues such as establishing specialised clinical services across the country where polio survivors can get the expertise they need to live as independently and actively as possible.

Polio Australia actually exists as an incorporated organisation with its Management Committee made up of state Network representatives, but no dedicated staff or premises. If anyone knows of any generous, philanthropic millionaires with a soft spot for post polio syndrome, my email is ALWAYS open – polio@independenceaustralia.com

**2009 Polio Day** is moving along and will be based on the theme "Health & Wellness Try Day". After last years' eight regional Polio Day's, I have had to reign it back in to one metropolitan day. Ideally I would have liked to have run one metro and one or two regional Polio Days but I simply don't have the resources for that this year. Polio Day will be held on Monday 12th October at Darebin Community Arts & Entertainment Centre in Preston, which is close to all forms of transport and has ample free onsite parking. Details will appear in the next Spring edition of Polio Perspectives.

As we have had no new nominations for the **Polio Advisory Committee**, there is no need for an election this year. The three existing members whose terms were up have re-nominated and will now continue on for another two years. However, we do need to second someone to replace Margaret Cooper who must stand down after having completed three consecutive terms. Margaret has been a passionate and active contributor to the PAC and she will be missed. If you are interested in finding out more about the PAC, please contact the Chairman, Michael Judson – Ph: 0412 302 997 or Mary-ann Liethof – 9418 0411.

Finally, we are still looking for many more of your '**Glimpses of Polio**' stories/photos/memoirs. Remember that we are specifically looking for contributions detailing a specific and significant event in your life rather than whole life stories. Please note that stories you may have contributed in the past are not being reviewed for this project as we are not in a position to use or edit stories without your signed "Statement of Informed Consent" form located at the bottom of Page 10 in the Autumn 09 edition of Polio Perspectives. If you would like another copy of this form, just email or ring Mary-ann. •

Hoping you find a nice, warm place to be this winter – **Mary-ann Liethof**

# Living with Polio in the 21st Century conference

→ continued from front page

really do for us and how important it was for them to be part of the experience, which they embraced just as we all had. These 'caregivers' were included in all activities and they had a special session – 'caregivers coffee' – where they sat and chatted and just had some time out for themselves.

Each day was jam packed with activities; it was hard to choose what you wanted to do because everything was so interesting and important to go to. But choices had to be made and that was one of the things that I learnt – you have to make choices in your life that will benefit you, and that you don't over commit to doing too much. I hope I can put into practice the art of making a choice and that hopefully, it will be the right one.

At one of the sessions it was mentioned that you should try something different, experience something new. Well one of the things that I really wanted to try was adaptive cycling which I did. They combined a wheel chair with a bicycle which I peddled by hand. It was great fun but hard work.

Dinner was at 6.00pm. Each night was a different theme. The second night was a cookout (BBQ) followed by a campfire sing-along where Mary-ann taught us "Bella mamma" (beautiful mother) which became the camp theme song – we Aussies made a great impression. Everyone was so relaxed and we all enjoyed each others company. It was such a great feeling.

On another night, we were shown the HBO film "Warm Springs". Watching the movie at Warm Springs itself, seeing the pools that Franklin Roosevelt exercised in, and hearing stories from people who rehabilitated at Warm springs was very moving. They all seemed to have had such a great time there. They were taken to physiotherapy, the hydrotherapy pool, and then to classrooms for lessons. They were encouraged to do everything. It seemed such a contrast to what I experienced here in Melbourne.

After these evening sessions we would go back to our common room and chat with the other lodgers whilst drinking wine and coffee (self supplied!). This was one of the many highlights of

getting to know our fellow survivors and their partners, just sitting around and talking – it was the best.

By the end of our time at Camp Dream I was totally exhausted and a little brain dead. There was really no time to rest. I didn't want to miss out on anything, whether it was chatting to new found friends or just sitting in the sun and relaxing – this was so important.

To summarise the Camp Dream Retreat experience; we had lots of interactive activities, I met some wonderful people from all over America and Canada, the days were long and exhausting, but we had great fun!

We then moved on to the 'Living with Polio in the 21st Century' Conference where some 400 people attended from America, Canada, and a number of other countries. The conference covered many of the topics from the Retreat, which gave us the opportunity to concentrate on other sessions one in which I was particularly interested in, 'Finding and Disseminating Information through Support Groups'. They did focus on internet communication, which I feel is OK for some, but in our group only a small percentage are computer literate and they're not keen to learn – they feel they are too old and it's all a little too hard to start something new!

Finally, the aim of attending the Wellness Retreat and Conference was not just to learn about myself and what can I do to improve my lifestyle, but

to share these experiences with you. The key things I learnt at Warm Springs are: I need to make choices; I need to exercise in moderation; rest/don't overdo it; listen to my body; change my lifestyle/work; and try something new. I also realised that I can travel, not be self-conscious about using my crutches, and asking for help whenever I need to. My mantra now is 'conserve it to preserve it'.

## Liz Telford

Polio Advisory Committee Member

The most remarkable experience for me about being at Warm Springs was being in the majority. I don't think I had ever been with a large group of people who had had polio. Even at social events or rehab attended as a child, people there had a range of conditions, and not many that I met had polio. My upbringing and coping defence had been to play down or even ignore the polio. I focussed myself and everyone around me as much as I was able, away from it.

Being immersed in the polio community for the four days of retreat and the three day conference gave me the chance to see the world from a completely different perspective, one where polio was mainstream and of great interest. It was also a world where it was the norm to use some sort of aid to get around. It was the norm to have to consider pacing and conserving energy. While there were distances to cover, it was stair free. Heavy doors had push-button mechanisms or anticipated you approaching and opened automatically.

*continued on page 4*



Liz asking David Oshinsky to sign her book

# Living with Polio in the 21st Century conference

→ continued from page 3

When my hip pain flared up people noticed and I found myself with a scooter. This was a new experience and I loved the freedom it gave me. Usually using one crutch and managing the pain and discomfort, I suddenly felt less constrained. Rather than concerns about how this would look or how others would react I was focussed on how it would enable me to do what I wanted. I played Bocce, did Tai Chi and Yoga, all seated. No concerns about whether I could adapt. I attended lectures and discussions on issues that pertained directly to me; bracing, pain, fatigue and exercise. However my main learning came from the people I met and through reflecting on my inclusion in this world

I met people for whom polio had impacted in similar ways to me and others whose stories were strikingly different. Attending a Post-Polio Health International meeting and hearing representatives from Africa, India, Pakistan, Japan, Germany, Canada and other countries describing the needs of polios had a profound effect and made me aware that there is an overriding narrative that links us. Although the radically contrasting conditions for those living with polio in the third world make this connecting story a painful one to face, locating myself in this broader context was somehow liberating. I realised how much I have tried to adapt myself to the 'normal' world and played down this aspect of who I am.

I began to see that my fear of being defined by polio had ironically denied me the opportunity of the chance to know and be known in my capacity as a person with this significant experience.

David M. Oshinsky, the author of *Polio: an American Story*, gave a compelling keynote address which described the political and social history of the polio epidemic in America and the enormous significance of President Franklin Roosevelt in that story. Commenting in his book on the impact of President Roosevelt writing back to each person who wrote to him, Oshinsky quotes that the recipient was "distinguished for what he had, not for what was missing." (p 47) This encapsulates the central shift in my own thinking that was made possible by my visit to Warm Springs. •



Fran at Art Therapy session, Roosevelt Warm Springs International Conference

## Fran Henke

Mornington Peninsula Post Polio Support Group Member

This is pretty much my emotional response to what was a very special and challenging trip.

We Victorians stayed the first night at Kress Hall, built in 1930, full of period charm. We took over, turning the lounge room into an internet cafe and had a great time, nicking out for dinner at a restaurant in the touristy township rather than facing the cafeteria and southern fried everything just yet.

The retreat over the first four and a half days at Camp Dream, which is part of the 900 acre Warm Springs property, with just 62 people, became a like family get-together. Moving to Camp Dream was a slight culture shock, a reminder of institutional days. We soon got over that, getting to know the welcoming Americans who couldn't believe we'd come so far.

The first session was on 'Body' and the definitions of post polio syndrome and diagnosis, which Dr Fred Maynard described as a diagnosis of exclusion. It was just semantics to try to differentiate between PPS and Late Effects of Polio, he said.

Aquatics was supposed to be next on the agenda, but the boiler was not working so the pool was closed. A big disappointment to all of us wanting to get into the mineral springs. The historic pools we saw in the film were closed for structural reasons – filled only once a year for a fundraiser. Went

instead to a seated exercise program. Later we tried sitting down Tai Chi and came away with instructional videos. Will we try it at home? Hope so.

The distance between the lodges, the dining hall and session venues became my undoing physically. I realised I manage at home within a comfort zone. By day two I'd decided to attend only sessions held in the dining hall at Camp Dream rather than try to make the rehabilitation centre on the other side of the lake - until they rashly gave me a golf buggy to drive over! Wrong side of the road, out the in of one way streets - fantastic! This experience, added to having access to a wheel chair in Atlanta, was profoundly liberating and will ease me into what ever transport I need next.

The session on 'Mind' left a questionless audience, so to fill the gap I asked about memory and repressed memories, which set off a train of questions, mostly unanswerable but resulted in many encounters later with people who had similar issues. These personal encounters were probably the richest learning and sharing times of the visit.

The presence of President Roosevelt was extremely strong – especially when we visited the Little White House that he built on the property during his four term presidency. Later seeing the film 'Warm Springs' (for the third time) was extremely moving. Survivors and staff who had been there during his time told wonderful stories of being around him, keeping his spirit of 'care with dignity' alive.

Then it was onto the main conference with more than 400 people from a dozen countries attending. The session on fatigue filled the auditorium. The notes said fatigue was the number one concern of post polio survivors with pain coming third. Never did find out what came second. Reasons for fatigue given were: high demands of daily activity, deconditioning of muscles – sedentary lifestyle, inflammation, brain damage, psychological and social issues, sleep, anaemia, depression.



The Polio Hall of Fame

People were surprised at the lack of focus on cognitive fatigue, leading to more huddles afterwards.

The second session on fatigue offered solutions: energy conservation, lifestyle changes, pacing, regular rest, devices such as scooters. Aerobic exercise to increase functionality and sleep studies were recommended. Needs multidisciplinary team management – if you can find it.

My next interest was the talk on current epidemics, but didn't take a hanky. The pictures of children crawling around in the dust in India and Africa were devastating. Rotary International's

provision of three wheeled hand operated trikes brought freedom of mobility to those lucky enough to have one. During a chat in the pool, Dr Fred Maynard commented that children in the current epidemics are generally affected from the trunk down, so the trikes serve them well.

The best presented session of the conference for me was the last, given by Professor David Oshinsky who won a Pulitzer Prize for his book "Polio: The American Story". He was articulate and interesting as he talked about the development of the March of Dimes as a way of moving FDR politically away

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# Pakistan's polio team responds to crisis

Global Polio Eradication Initiative  
20 May 2009

IMMUNIZATION teams continue to vaccinate children fleeing the ongoing military operation in Swat, Buner and Lower Dir Districts in north-west Pakistan for camps to the west and south. To date, nine transit points established along the routes to Malakand, Swabi and Mardan have immunized 17,850 children under five with trivalent oral polio vaccine (tOPV).

In the 26 established camps, where more than 87,000 people are now living, mobile teams have gone tent to tent, immunizing more than 6,890 children with tOPV and measles vaccine.

As of this week, 951,969 people were registered as Internally Displaced People (IDPs) in Pakistan. Of these, 868,936 people, or 91% of the total, are currently registered as living with host families. As a result, it is critical that the upcoming National Immunization Days, planned for 28-30 May, targeting 33 million children using tOPV, is of the highest possible quality. To that end, the polio programme is working to thoroughly map out the existing displaced population, to ensure comprehensive coverage.

Since August 2008, none of the target population in Swat (377,000 children under five years of age) have been vaccinated, with the province being inaccessible to immunization teams due to the security situation.

Meanwhile, the Pakistan program responded to two wild poliovirus type 1 cases in Multan district in the past two weeks by immunizing 191,266 children with monovalent oral polio vaccine type 1 in a localized area around the two cases. As of 19 May, 2009, Pakistan has reported a total of 13 polio cases - seven type-1 and six type-3 cases. •

Source: [www.polioeradication.org](http://www.polioeradication.org)

## Wild Poliovirus Weekly Update

Data as at 19 May 2009

Source: [www.polioeradication.org/casecount.asp](http://www.polioeradication.org/casecount.asp)

Total cases	Year-to-date 2009	Year-to-date 2008	Total in 2008
Globally	436	453	1652
- in endemic countries	318	432	1506
- in non-endemic countries	118	21	146

Country	Year-to-date 2009	Year-to-date 2008	Total in 2008	Date of onset of most recent case
CAR	2		3	3 May 2009
India	43	229	559	29 April 2009
Nigeria	256	187	799	24 April 2009
Pakistan	12	9	117	21 April 2009
Afghanistan	7	7	31	19 April 2009
Kenya	11	0	0	12 April 2009
Angola	6	5	29	11 April 2009
Guinea	1	0	0	9 April 2009
Côte d'Ivoire	10	0	1	6 April 2009
Sudan	33	1	26	4 April 2009
Chad	1	2	37	1 April 2009
Togo	6	0	3	28 March 2009
Benin	17	0	6	25 March 2009
Niger	13	6	12	23 March 2009
Burkina Faso	9	0	6	16 March 2009
Uganda	7	0	0	21 February 2009
DRC	1	2	5	10 February 2009
Mali	1	0	1	4 January 2009
Ghana	0	0	8	8 November 2008
Nepal	0	3	6	15 October 2008
Ethiopia	0	1	3	27 April 2008

# Noticeboard

## Restless Legs Syndrome (RLS)

by Ted Sands

I have been meaning to send you an email regarding the above. I contracted polio in 1944 and spent two years in a frame. Later on I went to Yooralla, I think primarily to give my mum a break! In adult life I served in the Navy for nine years, police force for 15 years, and competed internationally in swimming and pistol shooting with the Australian Police Team in 1984!

I guess I am lucky in some ways to have the mobility that I do. My reason in writing is to advise that for RLS I was taking Panadol or Mersyndol to allow me to sleep. Three years ago a nurse in Brisbane said to try calcium/magnesium tabs. I did, and they now allow me to go to bed and sleep at least some of the night. I guess after 30 years of shift work by body is programmed to wake after two or three hours. I go back to sleep eventually. These tabs have given me enormous relief and maybe some other polio sufferers may experience similar benefits.

I enjoy reading the mag and hope that even one person may benefit from my experience.

Many thanks, Ted – keep up the good work.



## NPS recommendations on natural, alternative and complementary medicine information

11 December 2008

Recommendations have been made to Government following research conducted by the National Prescribing Service Limited (NPS) into the complementary medicine\* information needs and uses of consumers, GPs and pharmacists.

In the final reports released today, NPS suggested a series of strategies and activities to ensure Australians are using complementary medicines safely and effectively.

Preliminary findings from the research showed consumers do not have ready access to adequate information about complementary medicines to inform their decision making. It was also revealed that many people do not tell their GP or pharmacist when they are taking complementary medicines; and consumers, GPs and pharmacists cannot easily find independent and accurate information about complementary medicines.

“This research has provided us with a solid base to explore options for further work to improve the quality use of complementary medicines,” NPS CEO, Dr Lynn Weekes said.

“Complementary medicine use is increasing in Australia as people are taking more responsibility for their health and turning to preventative measures. It is therefore vital that the average person has access to accurate information resources so they can make informed decisions about their health.”

Recommendations based on the NPS research include:

- Ensuring healthcare professionals have access to independent, regularly updated and evidence-based resources on the Internet, in clinical software, phone advisory services and in paper format.
- Including complementary medicines



in the drug lists and prompts in computerised prescribing systems and dispensing systems to allow for easy inclusion in patient records.

- Further research into how complementary medicines interact with conventional medicines, and how to ensure that consumers balance the risks and harms of both types of medicine.
- Regular articles on the benefits and safety of complementary medicines in professional journals and the inclusion of complementary medicines learning modules in professional development programs.
- Developing and incorporating complementary medicines curricula in undergraduate, postgraduate and continuing education for pharmacists and GPs.

The reports, which have been sent to the Department of Health and Ageing, conclude that any initiatives should focus on areas where the risks and benefits of complementary medicine use are greatest, and should involve a coalition of relevant stakeholders.

“We know consumers seek advice and purchase complementary medicines from a range of health workers including pharmacy assistants, health food store workers, naturopaths and other complementary, natural and alternative medicine practitioners. NPS hopes to be involved in further research to enable us to understand the information needs of these groups,” Dr Weekes said.

*\* Complementary medicines, also known as natural or alternative medicines, include herbal medicines, vitamin and mineral supplements, other nutritional supplements, traditional medicines such as Ayurvedic medicines and traditional Chinese medicines, homoeopathic medicines, and aromatherapy oils (where they make therapeutic claims).*

## Victorians Called on to Check Up on the Elderly and People with Disabilities in Major Emergencies

Media Release – 7 April 2009

Victorian seniors and people with disabilities will receive telephone check-up calls and personal visits before and during heatwaves, bushfires, floods and other significant emergencies as part of a \$1 million Brumby Government initiative.

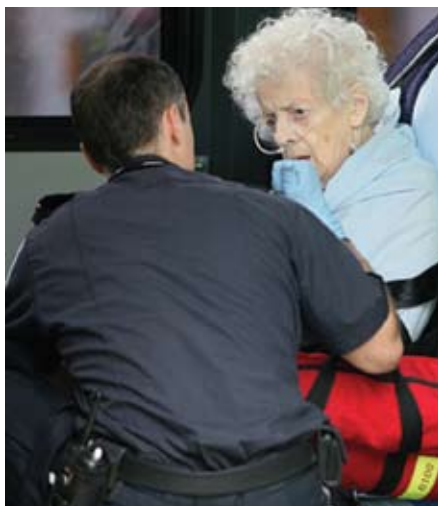
Senior Victorians Minister Lisa Neville today announced the funding boost which would see the roll out of a statewide Seniors Register program, with community volunteers to check up on elderly and people with disabilities who have registered with the program.

Ms Neville called on Victorians to sign up to become community volunteers and check up on elderly people in their communities, as part of the Victorian Government's Respect Strategy.

"Through the bushfires, we have seen the very best of the generous nature of Victorians. We need to make that last – and the best way to do that is to encourage young Victorians to get involved and look out for vulnerable members of our community."

Under the Seniors Register, elderly Victorians and people with disabilities can nominate to join the register. They provide contact details, their address and next of kin information.

Each local register is securely held within a participating Victoria Police station. Approved volunteers can



then enter the police station and contact registered people to check on their welfare.

In emergencies the registers are blitzed to ensure the safety, security and well being of registered people. If there are any concerns raised, emergency services are despatched to the address and next of kin contacted.

People wishing to take part in the Register can call the Office of Senior Victorians on 03 9208 3855.

Ms Neville said the Brumby Government would also spend \$1.4 million to help all local councils develop and implement heatwave strategies to better support local residents.

### Centrelink – Mission Australia by Joan Smith

I thought others in the polio community may be interested to hear of my recent experience with Centrelink. Although I have a fixed pension from my superannuation, I wanted the benefits of a health care card. Part of the process involved a job capacity assessment and I was directed to attend Mission Australia in Heatherdale road in Ringwood.

I arrived, armed with some of our group brochures as well as useful articles I'd saved, explaining post-polio symptoms. The assessor used the articles to inform her report and thanked me for teaching her about a 'new' chronic condition. My role as support group convenor adequately met the requirements for voluntary work.

After the assessment, I requested she share the information I had taken to assist others, staff and clients through the same process, and for general reading in the reception area. Mission Australia requested fifty more of our brochures, so I am pleased that I made some head-way in educating others about post-polio syndrome while I am reaping the benefits of the health care card.

I hope others feel encouraged by my experience and feel confident about using educational material to help achieve good outcomes for themselves.



### Waterproof KAFO

by Darren Pereira

A waterproof Knee Ankle Foot Orthosis (KAFO) has been in development over the last 12 months. Many clients, who wear a KAFO for walking, prefer to stand in the shower instead of using a shower chair. This functional activity often exposed the client to a very significant falls risk and further reliance on the good leg for full standing support.

Five polio clients now wear a waterproof KAFO. The design is a total contact laminate with full lining if required. It can be any colour, designed to be strapless if required and has its own build-up/waterproof tread. Although primarily for showering, clients are now utilising the KAFO for swimming, around the pool, surf fishing and general beach outings.

### NeuroMuscular Orthotics

As indicated in the Autumn Edition of Polio Perspectives, Darren Pereira is no longer working with Polio Services Victoria (read more about PSV changes on Page 12) but can still be consulted at his recently relocated private practice:

NeuroMuscular Orthotics  
Suite 29, 15 Ricketts Rd  
Mt. Waverley VIC 3149  
Ph: (03) 9543 4009  
Fax: (03) 9543 4991  
Email: enquiries@neuromuscular-orthotics.com.au  
www.neuromuscular-orthotics.com.au

# Surgery: Another Point of View

by Nancy Baldwin Carter, Omaha, Nebraska, n.carter@cox.net

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**A few years ago an orthopedic surgeon suggested rotator cuff surgery for me. “You could raise your arms,” he said. He saw the inactivity in my shoulders and wanted to help.**

“But I have no serratus,” I replied, remembering how my first polio doctor flattened his hand wide and moved it from my ribs around to and beneath my shoulder blade area to demonstrate the location of this broad muscle. Only when he pushed hard on my scapula, no longer served by the serratus, could I even begin to raise my arm. I understood why I need that muscle.

The orthopedic surgeon looked puzzled for a moment and finally said, “Oh. Then the surgery won’t help you raise your arms.”

He had been thinking of his experience with rotator cuffs, not my experience with muscles.

Herein lies a **RED LIGHT!** when it comes to polio survivors and certain types of surgery. Let’s say I have a problem I can see is getting worse. I don’t want to lose function. I want desperately to be put back together again, maybe even to become “the way I used to be.” I know that surgeons want equally as much to help their patients, to bring a missing quality back to their lives. Here’s the important part: I cannot allow my thought process to stop here, or I might find myself in deep trouble.

## **FUNCTION CANNOT ALWAYS BE RESTORED.**

This is hard for some to swallow. How can we be sure we are not allowing our desire to be made whole again to lead us to believe an uninformed surgeon can make our dreams come true? When should we trust? What risks are involved? Sometimes we simply need to put our common sense to work and make sure we’re dealing with reality.

## **A Surgery Story**

A 40-year polio survivor in her fifties wore a full leg brace on her left leg. Her right leg had a slight recurvation (bowing back from the knee down) problem, but did not require a brace. That leg worked well when she walked, climbed stairs, got up from the floor.

The head of orthopedic surgery in a teaching hospital examined her and proposed surgery in the right leg. He said he could correct the bent-leg condition and also wanted to transplant a hamstring in that leg to the quad, which he said would result in strengthening the quad to give more mobility. He saw this as a bonus to the recurvatum surgery and said, “I can make that leg stronger and prevent recurvatum from happening again.”

**RED LIGHT!** “I didn’t know if the recurvatum would be a problem later on as the doc said it would be,” says the woman. “The doc said he could keep the condition from becoming worse, and I believed him. He said he had studied with a Warm Springs doctor, and this helped convince me that he knew what he proposed would work.”

**He did not warn me of any consequences — everything was positive. I simply trusted him.”**

## **Results**

After a much longer recovery time than anticipated, the transplant didn’t work. Nobody had checked the quality of the hamstring, which therefore lost strength without gaining the expected strength in the quad. The woman can no longer bend that right knee back, requiring a locked full leg brace for walking. She can’t do steps as she did before or get up if she falls down. She can’t drive a car without hand controls, and balance problems make it difficult to get into a car on the passenger side.

**RED LIGHT!** “Today I know a good physical therapist should have checked the muscle strength before the surgery,” says the woman. “I wasn’t aware enough to realize this was something I could have taken care of myself.”

The recurvatum surgery left her with a pin improperly placed below the knee. Nerves to the right ankle were cut accidentally so she can no longer move her right foot to the right or lift it up, essentially giving her a drop foot. The necessity for using two full leg braces put a bigger burden on her shoulders and arms, causing them to deteriorate more quickly.”

## **Emotional implications**

“This surgery essentially left me with a second disability to cope with,” she says. “It prevented me from doing activities that I had done nearly normally before.”

“I am more angry now than I was at the time of the surgery, because I realise the gravity of what actually happened to me. I never really thought about living with disability until after that surgery. It has to do with independence—the fear of becoming dependent.”

“When I had one good leg, I had better balance and could carry things. Now I use a power chair because doctors have determined I should not add to my shoulders’ task by using crutches.”

**RED LIGHT!** “The surgery presented much more of a risk than I imagined. I’m disgusted with myself for not investigating more thoroughly in the beginning. I guess the idea of having a ‘normal’ leg again swept away my reasoning powers,” the woman concluded.

## USING COMMON SENSE

Avoiding **RED LIGHTS** becomes an important step in any surgery decision. Here are some tips to consider.

## Rehabilitation

- Be sure surgery is necessary, that it’s the best answer. Therapists with post-polio training, among others, can frequently devise ways of dealing with situations that preclude surgery. Pain, for example, can often be alleviated by physical therapy, exercise, learning not to overdo, or bracing. These methods can be much less complicated, expensive, and chancy. Even accepted alternative medicine approaches (such as acupuncture, massage, Yoga) may be encouraged by doctors, allowing both disciplines to work successfully together. Try the easy route first.
- Get rehab people lined up before the surgery. Have them determine your muscle strength/capability. Discuss the working of involved muscles with them and get their professional judgment of how the proposed surgery will affect those muscles. Share their findings with your doctor as you plan for the surgery.
- Discuss future needs with rehab experts. Can you count on certain muscles to behave the way you anticipate during recovery? Will your arm be able to aid in transferring the way you expect, for instance? Should you have additional equipment on hand for moving around, for bathroom activities, for other daily tasks and desires?

## Doctors

- Find the right doctor. Ask lots of questions. How many surgeries has he done that are similar to the one proposed? Is she qualified to work with the vagaries of polio muscles/bodies? Are you convinced this surgery involves doing something that can be done? Does your doctor see this surgery as a last resort? Are you listening with an inquisitive mind, looking for down-to-earth solutions?
- Get a second opinion from an expert not affiliated with your doctor. A little more caution can put minds at ease when making important decisions.

## Anesthesia

- Talk to your anesthesiologist well ahead of the surgery about your specific post-polio anesthesia issues — what to watch for, what to avoid, what to do. Consider, for example, that polio survivors are often sensitive to sedative medications such as certain muscle relaxants. Doctors should consider carefully the dosage of whatever they’re using initially. Care must be taken to prevent intraoperative overdose.
- Discuss post-operative pain with the anesthesiologists. Bring up that using local anesthesia at the incision plus PCA (patient controlled analgesia) may be one way to prevent pain. Or that succinylcholine should be avoided if possible, because of the severe muscle pain it can cause.
- Realise it’s possible for anesthetics to cause such temporary problems as gastroesophageal reflux, tachyarrhythmias, and even maintaining blood pressure. Ventilatory function should be discussed. Anesthesiologists should be made aware of upper airway and swallowing difficulties. Special care must be taken so that affected limbs are not fractured. Talk about these issues. Have your doctor arrange for you to have the same anesthesiologist you met with.



## In addition...

- If possible choose a hospital that uses a team approach. Doctors, therapists, technicians, counselors, planning together, coordinating their efforts, are more likely to make your experience smooth and successful.
- Do your research. Use the Internet and other reliable resources for sound suggestions and explanations.

Unfortunately we have no definitive list of surgical procedures that always work well for polio survivors—nor do we have one for dreamers to avoid. But we can learn to take precautions that leave us glad we spent the time to check things out.

I got lucky nineteen years ago when I needed truly challenging spine surgery. Fate stepped into my life and sent a brilliant doctor to watch over me. Everything clicked into place. I felt totally safe. I knew this was right for me.

It isn’t always this way. I’ve been told that I was in denial (when I refused to confirm I was having gallbladder pain when I was not), and that I was not cost effective (when the dental surgery I needed took more time than the surgeon wanted to give). When I get these clues I move on, find another doctor, search for better answers. **Maybe I need surgery; maybe I don’t. I’ll locate a good doctor and look into it. Mainly what I need is to play it smart.** •

# Good Thinking

by Dr Andrew Sinclair  
Independence Australia Psychologist



## On Being a Difficult Patient

In a recent essay in the online journal Health Affairs, Michelle Mayer, a research professor in America with a chronic illness, talks about why she eventually became a 'difficult patient' and how it helped her to get the medical care she needed.

As a health psychologist, apart from a focus on the challenges of living with chronic illness and disability, I am also interested in doctor patient relationships. Specifically how the quality or lack thereof of these relationships can influence the care a patient receives. In the course of my work I have often considered the plight of the 'difficult patient', particularly with my work with people who have had Polio.

These clients often talk of the frustrations of having their health care needs met, and how their doctors react to their behaviour, which often leave them feeling that they were themselves 'difficult patients'.

In her essay Michelle talks of how she frequently challenged her doctors with questions, sought out experts and second opinions and too often chose a treatment that differed from what her doctors recommended. Indeed if it was not for her assertiveness, she may never have been correctly diagnosed in the first place.

While Michelle considers herself an assertive patient for these behaviours, it was often clear to her that some providers thought she deserved the difficult label.

However for Michelle at least she didn't start out this way. Becoming difficult was not her first choice. All too often Michelle's care involved brief, problem-focused medical visits that were a poor substitute for the patient-focused encounters that her chronic condition required. To empower herself in such a system Michelle armed herself with information, asked questions, challenged treatment options, terminated relationships with unhelpful doctors and found like minded doctors willing to inform rather

than dictate her treatment options. Michelle doesn't regret becoming a difficult patient, but she does regret that so many people must settle for substandard care because they lack what it takes to advocate for their own needs.

If you are frustrated with the quality of care you are receiving and finding it difficult to advocate for the care you deserve you may benefit from some assertiveness training.

Please contact me at the Psychology Service for information and resources that might assist you to achieve what you need. However, if you are already acting like a 'difficult patient', in terms of your health care, this might be just what the doctor ordered. •

To read Michelle's essay in full go to **Health Affairs** – <http://content.healthaffairs.org/cgi/content/full/27/5/1416>

or simply Google 'On Being a Difficult Patient'.

## Living with Polio in the 21st Century conference

→ continued from Fran Henke on page 5

from polio and putting dealing with the epidemics on a national footing. With it all over, we went back to Camp Dream for a swim in the now heated pool – absolute bliss in the warm waters surrounded by oak and pine forests, populated with deer, squirrels and bird life. The environmental weed was wisteria!

The farewell dinner was a Low Country boil, with square dancing and music. After that we repaired to our lodge where a couple of well organised former politicians from different ends of the globe, produced bottles of wine. Discussion was energetic and fun.

We made great friendships during that week – with people from Canada to

Florida. The dedication of the carers who came was beautiful to see – and did we dog-deprived folk spoil Penny, the companion dog, against all recommendations! With John Tierney from NSW on board, we headed back to Atlanta after fond farewells from people we felt we'd known all our lives.

Mary-ann, Liz, Shirley and I toured Atlanta by carriage and cab to get the feel of the place from its colonial mansions to downtown slums where Martin Luther King moved African Americans to freedom. Hard to believe such diversity could exist in one city.

My take home feelings? Firstly personally, that pushed out of my comfort zone, I'm not the polio

survivor I thought I was – need more help with mobility, better assessment of capabilities. For us in Australia, I'm not sure yet on what front to continue the fight. We are assertive and articulate and probably will have to continue our battles for services locally unless Polio Australia takes off as a force on our behalf.

For the children with polio in Asia, my aim is to produce postcards or a children's book to sell in order to buy as many of those three wheeler trikes as possible. Rehabilitation of those children is the responsibility of their countries' health systems, meager though they are, but at least we can help them out of the dust. •

# My Story

by Leon Farrell

**Leon Farrell was born in Pooncarie NSW in 1939 and spent his early childhood around far west NSW until the age of 7.**

He started formal schooling in Wilcannia, boarding at the Convent for two years. The family returned to Pooncarie where he attended the school until at the age of 12, at which time he contracted polio and was admitted to the Mildura Infectious Ward, some 90 miles from his home. Another girl also attending the school died the day Leon was taken to Mildura. He was unconscious for three weeks and received his fair share of penicillin around the clock for approximately three weeks.

During the thirteen months spent at hospital Leon's parents were only able to visit occasionally due to the distance from their home, and he experienced the hospitality of several clubs, i.e. Rotary, Apex and Lions with their many visits – be it to go for a ride in the specially built hospital bed on wheels built by the engineers at the hospital, or on the receiving end of a continuous supply of books and magazines. This includes the Encyclopaedia which he claims to have read from cover to cover – always searching for information and knowledge to satisfy his inquisitive mind.

**This curiosity led to one major misadventure as he wondered what would happen if you put a piece of wire into the two sides of a power point and then turn it on!**

The result was instant – it blacked out the whole hospital for a period of time. This resulted in an iron lung having to be manually operated by the staff until the power was restored about 20 minutes later. Meanwhile Leon, realising something serious had happened because everything had blacked out, went into hiding and was found in the splint room a couple of hours later. After a severe



talking to, Leon fronted the patient and apologised. In spite of that near disaster, they remained friends for the next several years. Many a time they reminisced about that day!

Leon went on to boarding school in Forbes where he completed his schooling and overcome many difficult times in learning to participate in activities which were easy for some, e.g. pumping up the bike tyre. He persisted in that task for half a day until he succeeded. Quite a feat with only one working hand.

He has achieved much throughout his life and is now helping others with a loved one in hospital. He and his wife, Helen, manage Mary Glowrey House\*, which is accessible accommodation near St Vincent's Hospital, Melbourne, mainly for country people who need to stay nearby. He has great compassion and a listening ear and feels this is one way to remember those who helped him all those years ago. •

\* Mary Glowrey House, 132-134 Nicholson Street, Fitzroy. Ph: 03 9417 3379.

## Praise for Police Conduct

by D.F. Walters

One stormy day, I was returning from a visit to a friend in Coburg when I found myself in trouble thanks to a series of train delays. I was able to get as far as Burnley Station but then had to disembark, only to stand in the rain for the next two and a half hours.

Police were on duty to control the hundreds of stranded train travelers. When Connex staff finally did arrive, it was only to advise us to get alternative means of transport as buses were delayed due to traffic lights and trees being damaged in the wind.

I was cold, wet and my body ready to collapse. In my 67 years I had never had to resort to "poor me" but my condition was such that I could not ask my body to do more.

I approached two young Police Officers saying I had a problem and had to ask for their help to get on the next available bus. No response. I then told them my energy was depleted, which is what happens in later years after getting Polio. The Officer then asked his partner to bring up the squad car and I was invited to sit in the back seat to wait. Half an hour later I was escorted to the bus, the Officer holding all back as I was allocated a position in the front seat.

I will always be extremely thankful for the thoughtfulness and care these two young Officers showed to a very tired, wet, and aching Polio Survivor. •

# Polio Services Victoria

Ph: 9288 3900



## Welcome Simon Mathieson, new Service Coordinator and Physiotherapist

Simon commenced in the role of PSV Coordinator and Physiotherapist in April 2009. He comes to PSV from Caulfield Hospital where he had been working

since 2003 in a mixed hydrotherapy, inpatient and outpatient rehabilitation role.

As a Senior Clinician Physiotherapist in Neurological Rehabilitation Simon has had experience in the rehabilitation of clients following polio, stroke, brain injury and other neurological disorders. Currently completing a Master of Public Health he has a strong interest in optimising the outcomes of rehabilitation in clients following neurological events.

## New Orthotist

PSV is also pleased to announce the appointment of a new Orthotist, Stephen Hughes, who commenced with PSV on Monday 25th of May.

Stephen will be working full time for PSV, which has increased from the part-time position previously available to PSV. PSV hopes that the increase in Orthotics hours will allow for improved access to orthotic review and repairs in the future and allow for the development of innovative service models to improve access to the service as a whole and ensure that the polio community in Victoria can get the help it needs faster when they need it.

## Clinics for 2009

PROVISIONAL CALENDAR – SUBJECT TO CHANGE DUE TO AVAILABILITY OF REGIONAL CLINICAL CONSULTING ROOMS.

**PSV – PH 9288 3900**

### Metropolitan

All metropolitan clinics are held on WEDNESDAY from 10am – 4:30pm

- June 17
- July 1, 15
- August 12, 26
- September 9
- October 7, 21
- November 18
- December 2, 16

### Regional

- Wangaratta Wednesday 8 April
- Ballarat Wednesday 3 June
- Mildura Wednesday 29 July
- Leongatha Wednesday 23 September
- Warrnambool Wednesday 4 November

# Polio Support Group Contacts

## Ballarat Post Polio Support Group Inc

Meeting: 1st Wed in February, then bi-monthly  
 Cliff Sewell ph: 5336 1557  
 Ruth Grose ph: 5332 4755  
 email: n\_grose@vic.australis.com.au

## Bairnsdale Post Polio Support Group

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

## Bayside Post Polio Support Group (Hampton)

Meeting: 1st Thu of every month  
 Shirley Glance ph: 9592 8212  
 Email: howshirl@optusnet.com.au  
 Peter Willcocks ph: 9578 5953

## Bendigo Post Polio Support Group

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

## Eastern Region Polio Support Group Inc (Box Hill)

Meeting: 3rd Sat of every month  
 Janice Gordon ph: 9874 5363  
 Tricia Malowney ph: 0400 640 624  
 Email: gordonjanice@hotmail.com

## Echuca Post Polio Support Group

Ring Group Contact  
 Di Lauder ph: 5859 6311  
 Email: di\_lauder@yahoo.com.au  
 Helen Murray ph: 5482 2132

## Geelong Polio Support Group

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

## Hume Polio Self Help Group (Wangaratta)

Meeting: 2nd Saturday of every month  
 Margaret Goodman ph: 5752 1347  
 Harry Wilkinson ph: 5722 1472  
 email: hagd@tadaust.org.au

## Knox-Yarra Ranges Polio Support Group (The Basin)

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

## Mornington Peninsula Post Polio Support Group

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

## Northern Region Post Polio Support Group Inc (Coburg)

Meeting: 1st Sat of every month  
 Rosslyn Pickhaver ph: 9386 0413  
 Jo McKenna ph: 9308 8440  
 email: rosslynp@tadaust.org.au

## 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

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

## South Eastern Region Polio Support Group (Springvale)

Meeting: 2nd Sat of every month  
 Lyn Bates ph: 9546 5497  
 email: lyn\_bates@bigpond.com

## Traralgon Post Polio Support Group

Meeting: 3rd Thu in February, then bi-monthly  
 Pauline Corrigan ph: 0424 714 720  
 email: pollyc5@bigpond.com

## Warrnambool Polio Support Group Inc.

Meeting: 4th Tue of every month  
 Bill Hill-Peters ph: 5561 3980  
 Anne Clapham ph: 5562 5685  
 email: anne.clapham@yahoo.com

## Wimmera Polio Support Group (Horsham)

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

## Polio Network Victoria – 2009 Support Group Visits

Support Group	Date
Knox-Yarra Ranges	Saturday 14 February
Echuca/Shepparton (joint meeting)	Thursday 12 March
Mornington Peninsula	Saturday 14 March
Bairnsdale	Tuesday 5 May
Bayside (Hampton)	Thursday 7 May
Geelong	Monday 1 June
Northern (Coburg)	Saturday 6 June
Bendigo	Saturday 20 June

Support Group	Date
South Eastern (Springvale)	Saturday 11 July
Warrnambool	Tuesday 28 July
Ballarat	Wednesday 5 August
Hume (Wangaratta)	Saturday 8 August
Wimmera (Horsham)	Saturday 5 September
Eastern (Box Hill)	Saturday 19 September
Sale	Friday 2 October
Traralgon	TBA