

Polio Network Victoria

Polio Perspectives

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News from Israel

by Liz Telford

IN 2007 a small group of polio survivors in Israel won a compensation claim against the Israeli government. This polio compensation is over and above all other benefits received as a disabled person in Israel. Yehuda Doron successfully lead the claim that the 2500 Israelis who had contracted polio in Israel are suffering now as consequence of lack of services and inappropriate surgery and also vaccinations received in the 1950s. The other 1500 Israelis who had polio but contracted it abroad or prior to 1948, are not entitled to the compensation. Yehuda who himself had polio in 1954 and Jacob Surany who contracted it in 1952 are examples of the many people who were subjected to inappropriate surgery, the only form treatment offered in Israel at the time.

Having read about this case in "Post-Polio Health", Post-Polio Health International's newsletter, I was intrigued that a group of polio survivors had successfully lobbied on their own behalf. I was further intrigued that this occurred in Israel, a country so full of competing needs and complex issues. I was to be visiting Israel in June with my

husband Ron to visit our daughter who is doing a 'gap' year there and decided it would be interesting to meet them to exchange stories of the experience in our two countries.

I contacted Jacob Surany who had written the article. Jacob responded very positively to my email and a meeting was planned. They would be very interested in hearing about our services in Australia, he said. For me this was also an opportunity to further explore the experience of having polio, something that I have become more interested in as I learn to manage post polio development.

We met in a restaurant in Netanya, a pleasant town on the Mediterranean about half an hour from Tel Aviv. What is notable about Netanya is the wheelchair friendly footpaths and the elevator to the beach. There are also ramps to the water and special water proof wheelchairs. Outdoor gym equipment was accessible and being used by people of all abilities. Compared to Jerusalem and Haifa this was wheelchair heaven and in the space of an hour and saw at least five other people in

wheelchairs enjoying the beachside cafes and activities.

At the meeting, besides Jacob Surany, were Yehuda Doron, Ira Taponova, advocate Yonatan Davidovitch, Valentina Davidovitch (the wife of Yonatan), Haya Keinan, Margalit Gabai and her son Jacob Gabai, who provided excellent translation between Hebrew and English.

Our main discussion was about the differences in responses to polio between our two countries. I used my own experience of having polio in 1956 to describe the context of Australian post-war services with Dame Jean McNamara and other specialists researching treatments and establishing the physiotherapy program I benefited from.

Meanwhile in 1956 the new State of Israel, just eight years old was already fighting for its existence and was building a modern economy. It was absorbing many thousands of immigrants and displaced people from post war Europe, other Arab countries and North Africa. A lot was going on but this did not stop the polio virus. Polio was contracted by 12,000 people in Israel and another three thousands had contracted it either abroad or before 1948 (in Israel). We heard that the treatment option for polio patients in Israel was surgery, and there were no polio specific physiotherapy programs. Post polio symptoms are severe as the surgery, which tended to be orthopaedic rather than tendon or muscle focused has lead to further complications. There are still no polio specific services.

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PAC MEETING DATES 2009

- 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

Well, Spring has just about ‘sprung’ and I, for one, am looking forward to those longer, warmer days. As I seem to muse in every quarterly edition of Polio Perspectives – where has the time gone? We are speedily approaching our **Health and Wellness ‘Try Day’**, which will be held on Monday 12 October (see pages 10 & 11 for details and Booking Form) during Polio Awareness Week 2009. We are very grateful to Darebin, Moreland and Yarra Councils for boosting our funding for the day and ensuring we can keep the costs down to \$10.00 a head.

This year have aligned our Polio Awareness Week with Post-Polio Health International’s (PHI) ‘We’re Still Here’ campaign, although we do diverge on the theme. PHI is focusing on ‘Improving Community Accessibility’, an undeniably worthy cause which everyone can get involved with. If you ‘surf the net’, check out the details on PHI’s webpage: www.post-polio.org/WereStillHere.html

Since returning from Warm Springs, USA, I have visited several **Polio Support Groups** to share some of the information I learned at PHI’s Polio Wellness Retreat and Polio in the 21st Century Conference. Those groups include Bairnsdale, Bayside (Hampton) – who were celebrating their first anniversary, Geelong, Northern Region (Coburg), Bendigo, South Eastern (Springvale), Warrnambool, Ballarat and

Wangaratta. More on the Warm Springs experience will be presented on Polio Day by fellow travellers Shirley Glance, Fran Henke, Liz Telford and me.

Before our Polio Day, however, I have been invited to speak at Post-Polio Network (NSW)’s One-Day Country Conference on Saturday 26 September in **Wagga Wagga**. Other speakers include Simon Mathieson from Polio Services Victoria and Sue Gorman from IDEAS (Information on Disability & Education Awareness Services). If this is a convenient location for you, contact Post-Polio Network on (02) 9890 0946 for details.

Whilst we’ve been gathering stories for the ‘Glimpses of Polio’ book project, the Knox-Yarra Ranges Polio Support Group has also been progressing on their own publication, **‘The Calliper Kids’**. The group has successfully sought funding grants from Shire of Yarra Ranges, Boronia Rotary (see page 12), Bendigo Bank, Ferntree Gully Bowling Club and a number of other small donations. They hope to launch the book early in 2010.

In this edition, you will also read about the **Polio Australia** delegation trip to Parliament House, Canberra in June (page 6). I joined Gillian Thomas, her husband Peter, and Neil von Schill from Post-Polio Network (NSW), and Dr John Tierney, ex-politician now working as a Government lobbyist. All our Australian state networks are working hard – and on a volunteer basis – to ensure that this national body attracts the funding it needs to employ staff and get established. Then Polio Australia can start working on its vision to ensure that all polio survivors have access to adequate support and information together with comprehensive, consistent health care from a range of well-informed and educated professionals. You can help by bending your own local MP’s ear today!

Hope to see you at the Health and Wellness ‘Try Day’! •

“Half the things that people do not succeed in are through fear of making the attempt.”

James Northcote

– Mary-ann Liethof

Music and the Power of Focus

Make the most of what you have, inner resourcefulness is always better than external resources

On November 18, 1995, Itzhak Perlman, the violinist, came on stage to give a concert at Avery Fisher Hall at Lincoln Center in New York City.

If you have ever been to a Perlman concert, you know that getting on stage is no small achievement for him. He was stricken with polio as a child, and so he has braces on both legs and walks with the aid of two crutches. To see him walk across the stage one step at a time, painfully and slowly, is an awesome sight.

He walks painfully, yet majestically, until he reaches his chair. Then he sits down, slowly, puts his crutches on the floor, undoes the clasps on his legs, tucks one foot back and extends the other foot forward. Then he bends down and picks up the violin, puts it under his chin, nods to the conductor and proceeds to play.

By now, the audience is used to this ritual. They sit quietly while he makes his way across the stage to his chair. They remain reverently silent while he undoes the clasps on his legs. They wait until he is ready to play.

But this time, something went wrong. Just as he finished the first few bars, one of the strings on his violin broke. You could hear it snap – it went off like gunfire across the room. There was no mistaking what that sound meant. There was no mistaking what he had to do.

We figured that he would have to get up, put on the clasps again, pick up the crutches and limp his way off stage – to either find another violin or else find another string for this one. But he didn't. Instead, he waited a moment, closed his eyes and then signalled the conductor to begin again.

The orchestra began, and he played from where he had left off. And he played with such passion and such power and such purity, as they had never heard before.

Of course, anyone knows that it is impossible to play a symphonic work

with just three strings. I know that, and you know that, but that night Itzhak Perlman refused to know that.

You could see him modulating, changing, re-composing the piece in his head. At one point, it sounded like he was de-tuning the strings to get new sounds from them that they had never made before.

When he finished, there was an awesome silence in the room. And then people rose and cheered. There was an extraordinary outburst of applause from every corner of the auditorium. We were all on our feet, screaming and cheering, doing everything we could to show how much we appreciated what he had done.

He smiled, wiped the sweat from this brow, raised his bow to quiet us, and then he said – not boastfully, but in a quiet, pensive, reverent tone – “You know, sometimes it is the artist's task to find out how much music you can still make with what you have left.”

What a powerful line that is. It has stayed in my mind ever since I heard it. And who knows? Perhaps that is the definition of life – not just for artists but for you and me too.

Here is a man who has prepared all his life to make music on a violin of four strings, who, all of a sudden, in the middle of a concert, finds himself with only three strings; so he makes music with three strings, and the music he made that night with just three strings was more beautiful, more sacred, more memorable, than any that he had ever made before, when he had four strings.

So, perhaps our task in this shaky, fast-changing, bewildering world in which we live is to make music, at first with all that we have, and then, when that is no longer possible, to make music with what we have left. •

Source: www.ericstherland.biz/articles/music.html



“You know, sometimes it is the artist's task to find out how much music you can still make with what you have left.”

Thoughts:

I got this story from Peter Thomson in his regular TGI Mondays newsletter.

If you enjoy motivational stories, please visit his web site www.tgimondays.com.

It is very easy to make excuses about why we cannot do something. “If only I had...” holds us back.

To move forward in our lives we need to get beyond these limiting beliefs and replace them with positive “I Can” beliefs.

– Eric Sutherland
Make the Connection

Red Cross warning on poor nation epidemics

A Red Cross official has sharply criticised “complacency” towards the impact of communicable diseases on poor countries, contrasting it with responses to flu or heart disease in rich nations.

A report released by the International Federation of Red Cross and Red Crescent Societies on Monday warned that the crippling and growing burden of epidemics like dengue fever, polio, or meningitis was not being sufficiently addressed.

“We do not see interest, we only see vague, uncoordinated interest in high-profile issues such as influenza – which is in itself a great risk, but not the only one,” said Tammam Aloudat, the federation’s senior officer for health in emergencies.

Swine flu has “killed so far about 150 people, the potential for risk is massive, but what we have today is 14 million people dying mostly unnecessarily from easily preventable diseases that require little resources,” he told journalists.

Titled “The Epidemic Divide”, the Red Cross report said a focus on death rates had helped increase attention and resources to tackle non-communicable diseases such as heart attacks and cancers, now the leading killers worldwide.

But the dominant threat in developing countries remains preventable infectious disease, and their societies were not only ailing due the huge mortality but also the debilitating impact of illness on their development. Resources to deal with such existing epidemics remained “scarce”, the report added.

Out of the limelight, mosquito-borne dengue fever kills 18,000 people a year and sickens nine million people annually, keeping them away from work and amplifying the failings of under-resourced health care, the Red Cross said. The report said “complacency” towards existing epidemics was “a major threat in itself”. It highlighted the resurgence of measles in Europe to underline that Western nations were not immune, especially with easy international travel.

Asked about the World Health Organization’s role in setting international priorities and raising attention, Aloudat said: “The global public health community could have done better, including ourselves.”

“I am saying that there are shortcomings on all sides... Unless all those people sit together and decide the agenda we are not going to win this one.” He also highlighted a shortfall in meeting UN development goals, which include health targets. “Complacency happens when goals are set and resources aren’t allocated,” the Federation doctor said.

A WHO-led immunisation campaign in the 1990s eliminated polio from more than 120 countries, but failed in its target to eradicate the lethal or crippling disease entirely by 2005.

Since then polio has re-emerged across Africa after donors lost momentum, routine immunisation dropped off and local obstacles emerged, according to the report. The Federation recently sought just 2.4 million US dollars for 80 million polio vaccines but has received less than half that funding.

Meningitis, which often surges to epidemic proportions in Africa, kills half of the people infected, while neglected emerging and re-emerging diseases affect about one-sixth of the world’s population, mainly in poor countries. The

report advocated more resources, immunisation, community prevention, better access to health services, clean water and sanitation in poor nations.

“What we are saying is: if we are going to be serious, it’s not influenza alone, it’s not any issue alone, it’s a whole connected subject,” Aloudat explained.

Source: *The Age*, July 6, 2009

Argentina Issues Polio Warning

by Estela Mccollin Williams

The Argentina Public Health Ministry issued a warning and adopted measures over a case of polio detected in San Luis Province, the first in 25 years.

Among recommendations are vaccinating the child and school-age population, keeping an eye on the source of the infection and issuing preventive measures.

A 15-month toddler was diagnosed with acute flaccid paralysis and gammaglobulinemia, a rare pathology that altered his immune system and allowed the onset of polio. Hospital sources said they were able to isolate Sabin 1 poliovirus, also known as derived Sabin virus, from the child’s fecal matter.

Doctor Alberto Cormillot, told the TV channel C5N that under World Health Organization standards, preventing the disease spread demands vaccinating 95 percent of the infant and school-age population. He regretted that some areas only had 85 percent immunization, paving the way for polio recurrence, hence the need to step up vaccination, which is free in Argentina.

Source: *Prensa Latina*, 2 June 2009, Buenos Aires

Polio surge in Nigeria after vaccine virus mutates

by Maria Cheng (AP)

LONDON — Polio, a dreaded paralyzing disease stamped out in the industrialized world, is spreading in Nigeria despite efforts to stamp it out. And health officials say in some cases, it’s caused by the vaccine used to fight it.

In July, the World Health Organization issued a warning that this vaccine-spread virus might extend beyond Africa. So far, 124 Nigerian children have been paralyzed this year — about twice those afflicted in 2008.

The polio problem is just the latest challenge to global health authorities trying to convince wary citizens that vaccines can save them from dreaded disease. For years, myths have abounded about vaccines — that they were the Western world’s plan to sterilize Africans or give them AIDS. The sad polio reality fuels misguided fears and underscores the challenges authorities face using a flawed vaccine.

Nigeria and most other poor nations use an oral polio vaccine because it’s cheaper, easier, and protects entire communities. But it is made from a live polio virus — albeit weakened — which carries a small risk of causing polio for every million or so doses given. In even rarer instances, the virus in the vaccine can mutate into a deadlier version that

ignites new outbreaks. The vaccine used in the United States and other Western nations is given in shots, which use a killed virus that cannot cause polio.

So when WHO officials discovered a polio outbreak in Nigeria was sparked by the polio vaccine itself, they assumed it would be easier to stop than a natural “wild” virus. They were wrong. In 2007, health experts reported that amid Nigeria’s ongoing outbreak of wild polio viruses, 69 children had also been paralyzed in a new outbreak caused by the mutation of a vaccine’s virus. Back then, WHO said the vaccine-linked outbreak would be swiftly overcome — yet two years later, cases continue to mount. They have since identified polio cases linked to the vaccine dating back as far as 2005.

It is a worrying development for officials who hope to end polio epidemics in India and Africa by the end of this year, after missing several earlier deadlines. “It’s very disturbing,” said Dr. Bruce Aylward, who heads the polio department at the World Health Organization.

This year, the number of polio cases caused by the vaccine has doubled: 124 children have so far been paralyzed, compared to 62 in 2008, out of about 42 million children vaccinated. For every case of paralysis, there are hundreds of other children who don’t develop symptoms, but pass on the disease.

When Nigerian leaders suspended polio vaccination in 2003, believing the vaccine would sterilize their children and infect them with HIV, Nigeria exported polio to nearly two dozen countries worldwide, making it as far away as Indonesia. Nigeria resumed vaccinations in 2004 after tests showed the vaccine was not contaminated with estrogen, anti-fertility agents or HIV.

Experts have long believed epidemics unleashed by a vaccine’s mutated virus wouldn’t last since the vaccine only contains a weakened virus strain — but that assumption is coming under pressure. Some experts now say that once viruses from vaccines start circulating they can become just as dangerous as wild viruses.

“The only difference is that this virus was originally in a vaccine vial,” said Olen Kew, a virologist at the U.S. Centers for Disease Control and Prevention.

The oral polio vaccine used in Nigeria and elsewhere contains a mild version of the live virus. Children who have been vaccinated pass the virus into the water supply through urine or feces. Other children who then play in or drink that water pick up the vaccine’s virus, which gives them some protection against polio. But in rare instances, as the virus passes through unimmunized children, it can mutate into a strain dangerous enough to ignite new outbreaks, particularly if immunization rates in the rest of the population are low.

Kew said genetic analysis proves mutated viruses from the vaccine have caused at least seven separate outbreaks in Nigeria. Though Nigeria’s coverage rates have improved, up to 15 percent of children in the north still haven’t been vaccinated against polio. To eradicate the disease, officials need to reach about 95 percent of the population.

Nigeria’s vaccine-linked outbreak underlines the need to stop using the oral polio vaccine as soon as possible, since it can create the very epidemics it was designed to stop, experts say. WHO is researching other vaccines that might work better, but none is on the horizon.

Until a better vaccine is ready, WHO and U.S. CDC officials say the oral vaccine is the best available tool to eradicate polio and that when inoculation rates are nearly 100 percent it works fine.

“Nigeria is almost a case study in what happens when you don’t follow the recommendations,” Kew said.

Since WHO and partners began their attempt to rid the world of polio in 1988, officials have slashed the disease’s incidence by more than 99 percent. But numerous deadlines have been missed and the number of cases has been at a virtual standstill since 2000. Critics have also wondered whether it is time to give up, and donors may be sick of continuing to fund a program with no clear endgame.

“Eradication is a gamble,” said Scott Barrett, an economist at Columbia University who has studied polio policies. “It’s all or nothing ... and there is a very real risk this whole thing may fall apart.”

Aside from Nigeria, polio persists in a handful of other countries, including Afghanistan, Pakistan, India, Chad, Angola and Sudan.

Aylward agreed the Nigeria situation was another unwelcome hurdle, but was confident eradication was possible. “We still have a shot,” he said. “We’re throwing everything at it including the kitchen sink.” •

Source: AP – Associated Press, 15 August 2009

Wild Poliovirus Weekly Update

Data as at 19 August 2009

Source: www.polioeradication.org/casecount.asp

Total cases	Year-to-date 2009	Year-to-date 2008	Total in 2008
Globally	839	1044	1651
- in endemic countries	621	980	1505
- in non-endemic countries	218	64	146

Country	Year-to-date 2009	Year-to-date 2008	Total in 2008	Date of onset of most recent case
India	206	359	559	31 July 2009
Pakistan	35	31	117	28 July 2009
Afghanistan	17	15	31	27 July 2009
Chad	13	12	37	15 July 2009
Nigeria	363	575	798	12 July 2009
Angola	19	23	29	8 July 2009
Guinea	15	0	0	6 July 2009
Liberia	7	0	0	29 June 2009
Côte d'Ivoire	24	0	1	26 June 2009
DRC	3	3	5	24 June 2009
CAR	14	1	3	22 June 2009
Kenya	17	0	0	30 May 2009
Sudan	44	3	26	28 May 2009
Niger	15	13	12	28 May 2009
Burkina Faso	12	1	6	20 May 2009
Uganda	8	0	0	10 May 2009
Benin	20	2	6	19 April 2009
Togo	6	0	3	28 March 2009
Mali	1	0	1	4 January 2009
Ghana	0	0	8	8 November 2008
Nepal	0	4	6	15 October 2008
Ethiopia	0	2	3	27 April 2008

Noticeboard

Restoring Balance

by Marion Kosseck, Geelong PSG

I would like to share with you how Dr Steven Sommer has really helped me cope with headaches, Irritable Bowel, pain and other PPS Symptoms. Hopefully by sharing my experience, others may also benefit. After being referred to him 6 months ago, I have found his methods of teaching me to breath correctly, relax, sleep better, control stress and anxiety have made such a difference in my life, particularly with pain relief. At last I am able to begin enjoying a better life by listening to my body and pacing myself.

I would thoroughly recommend listening to and following the program on the CD below. As Dr Sommer says "We all get better at what we practice. Learning to calm ourselves is no different. It is a wonderful skill that this CD can help you to learn".

Dr Steven Sommer M.B.,B.S FRACGP began teaching stress management in the early 90's whilst working as a GP and senior lecturer at Monash University's Department of General Practice. Recognising the need amongst his patients and medical students, he began by teaching them techniques to manage their stress. Soon he found himself presenting to groups of doctors, nurses, high school students and people from all walks of life. He has also been an invited Grand Round presenter on this topic at several major teaching hospitals.

Restoring Balance is a complete stress management program which teaches:

- Diaphragmatic Breathing – a 5 minute Senses Awareness Meditation
- Soften & Flow Meditation (for easing emotional and muscle tension)
- Progressive Muscle Relaxation (designed to aid sleep)
- Improves well being and can relieve: anxiety, insomnia, headaches, IBS and other stress-related disorders.

Restoring Balance CD's sell for \$25 each (inc GST) plus postage and handling of \$3 for 1 CD / \$5 for 2 or more. \$5.00 from each sale is donated to Polio Network Victoria.

Order Forms available from Mary-ann Ph: (03) 9418 0411 or Email: polio@independenceaustralia.com

Post Polio Syndrome: Shades of Grey

Have you seen the PPS: *Shades of Grey* (2009) DVD produced by Polio Network Victoria? This DVD is a series of videoed interviews with eminent North American Post Polio Specialists conducted during Mary-ann Liethof's Churchill Fellowship Study Tour in 2008. It is divided into 9 Chapters and best watched in stages:

- 1 About the participants
- 2 Clinical structures
- 3 Diagnosis
- 4 Managing symptoms
- 5 Therapists
- 6 Research
- 7 The big picture
- 8 Information: non clinical services
- 9 Future of Polio Services

Shades of Grey is available for sale through PNV*, on loan through your Polio Support Group and can be viewed for free on www.youtube.com/PolioNetworkVictoria

*\$16.50 plus \$2.50 postage and handling within Australia – contact Mary-ann on Ph: 03 9418 0411 or Email: polio@independenceaustralia.com

Polio Australia in Canberra



L-R: Darren Chester, Neil von Schill and Gillian Thomas (seated) – PPN (NSW), Mary-ann Leithof – PNV, Dr John Tierney (Lobbyist) and Peter Garde (Carer)

A delegation from Polio Australia visited Parliament House on 24 June to discuss funding for establishment and operations of this national body. Lobbying for Polio Australia is currently being done voluntarily by a sub-committee made up of representatives from the State Polio Networks Management Committee.

Following the June trip, Catherine King, Member for Ballarat, prepared a Private Members Motion which was read out in the House of Representatives on Monday 17th August. Ms King moved -

"That the House recognises that:

- 1 polio survivors continue to be the single largest disability group in

Australia today, numbering in the tens of thousands;

2 this number not only includes those who contracted polio in Australia during the epidemics last century, but also young polio survivors who have migrated from countries where polio is still prevalent or only recently eradicated;

3 the needs of polio survivors have been largely neglected since vaccination against the disease became a reality, and as they age with chronic disabilities this neglect must be addressed as a matter of urgency;

4 over the last 20 years much attention has been drawn to the development of new, previously unrecognised, symptoms which occur in people who were thought to have reached a stable level of recovery after the acute disease;

5 symptoms of the late effects of polio include unaccustomed fatigue unrelated to activity, decreased strength and endurance, pain in muscles and/or joints, an inability to stay alert, weakness and muscle atrophy, muscle and joint pain, muscle spasms and twitching, respiratory and sleep problems, swallowing and speaking difficulties, depression and anxiety.

6 over the last 20 years polio survivors have established state based post polio organisations to provide information and support for fellow survivors, and that these networks are run by polio volunteers who themselves are experiencing increased disability and decreased mobility; and

7 in the coming years it is increasingly inevitable that many state networks will cease to function as volunteers find themselves unable to continue the service, thereby creating the necessity for a central body, Polio Australia, to take over responsibility for state functions."

This Motion was also supported by Darren Chester, Member for Gippsland (Vic), Jill Hall, Member for Shortland (NSW), and Mark Coulton, Member for Parkes (NSW). A full transcript can be found at: <http://www.openaustralia.org/debates/?id=2009-08-17.121.1&s=polio#g125.1>

A follow-up visit to Canberra is scheduled for 24 November. In the meantime, the Polio Australia committee members are encouraging any members who have the ear of, or is willing to approach their local MP (particularly Federal) to contact them and ask if they are willing to meet with the Polio Australia delegation on the 24th November. Of course, to put this into perspective, the MP will want to

know what all this means for you, their constituent, so you should be prepared to tell your story.

To find out what you can do to, contact Mary-ann on Ph: (03) 9418 0411 / Email: polio@independenceaustralia.com in Victoria, or the Polio Network Co-ordinator in your state.

Premier announces reforms to health, community services and local government

Press Release: 12 August 2009

The Premier, John Brumby, today announced a major restructure of health, community services and local government functions to deliver better services to Victorian communities and families. Mr Brumby announced that a new Department of Health would oversee all health services, mental health, aged care and preventative health in Victoria, to deliver greater accountability in hospitals.

"I firmly believe that these changes will help deliver better services to Victorian families and communities," Mr Brumby said. "We are at a crucial juncture in health and hospital services in Victoria and Australia. Council of Australian Government reforms are lifting standards in our hospitals and reducing waiting times. A new Department of Health – focusing on hospital performance, mental health and prevention – means that Victorians can derive greater benefits from these reforms."

Mr Brumby said the health and human services task had grown significantly since the 1990s, accounting for nearly \$4 in every \$10 that the State Government invests in services, employing around 13,000 staff and more than 80,000 through its agencies. "These reforms are designed to increase the accountability, performance and focus of our health system, our family and community services and social housing," Mr Brumby said.

Mr Brumby said the new Department of Health would also better address the needs of Victoria's ageing population. "By 2030 there will be more than 1.4 million Victorians over the age of 65. The new Department of Health will focus on ensuring older Victorians can access the services they need," he said.

The Premier has appointed current DHS Secretary Fran Thorn as Secretary of the new Department of Health. The Minister for Health, Daniel Andrews,

remains coordinating Minister for this Department. He also announced a new Department of Human Services would oversee services for children, youth and families, housing, disability, concessions and bushfire recovery. Gill Callister is the new Secretary of the Department of Human Services. The Minister for Community Services, Lisa Neville, is coordinating Minister for the new Department of Human Services.

"The unfortunate reality is that cases of family breakdown are becoming more frequent and more complex. A stand-alone department is now needed to address rapidly growing demand on health and community services sector," Mr Brumby said.

"With a growing population and strong birth rates, it is a critical time for Government to ensure we can provide support to vulnerable families and children. Central to this will be addressing the workforce challenges and ensure we have the best and brightest case workers."

"Across Australia, we are also facing a workforce challenge in recruiting enough case workers for vulnerable children. Addressing this recruitment issue and providing greater clarity around decision making will be key priorities for the new Department of Human Services."

In further reforms, Mr Brumby also announced the establishment of a new Local Government Investigations and Compliance Inspectorate as an administrative office, to be headed by a Chief Municipal Inspector. "This reform will strengthen the ability to prosecute any breaches of the Local Government Act and strengthen the independence of investigations," Mr Brumby said. "It separates Local Government Victoria's two roles of policy leadership and enforcement of the Local Government Act."

The functions of the new Inspectorate include:

- Systematic spot audits of compliance with governance requirements in the Local Government Act;
- Investigating breaches of the Local Government Act;
- Monitoring corporate governance of councils;
- Investigating alleged breaches of electoral provisions;
- Undertaking prosecutions for breaches of the Local Government Act;
- Elevating matters of gross misconduct of a councillor to the Victorian Civil and Administrative Tribunal;

- Recommending to the Minister for Local Government that a council be suspended or dismissed for cases of serious failure in corporate governance.

Mr Brumby has also charged the Essential Services Commission with the development of a performance assessment and benchmarking regime for local governments.

Ministerial responsibilities remain unchanged under these new arrangements. There will be no job losses as a result of the reforms.

The Secretary of the Department of Premier and Cabinet, Helen Silver will chair the Transition Taskforce for implementing the restructure.

The Office for the Community Sector was established in the Department of Planning and Community Development to strengthen and support the not-for-profit community sector. More information may be found on: www.dpcd.vic.gov.au/communitysector

Introducing 'Bayside Villa' Independence Australia's respite home by the sea

Located in the cosmopolitan, bayside suburb of Williamstown, Bayside Villa is a newly renovated and well appointed holiday respite home that has been purposefully designed to accommodate the needs of people living with physical disabilities. Bayside Villa offers guests:

- 24/7 Attendant Care
- Single and double bed rooms available
- Dine in options
- Recreation room with library & games
- Lounge (TV, DVD, VCR, CD)
- Central heating & air-conditioning
- Guest Laundry
- On-site parking

Cost:

Bayside Villa is an unfunded respite facility which means that the cost of care is not subsidised and clients pay a daily rate for accommodation and meals. Accommodation rates are reviewed annually and available upon request. Cost may vary if active night or additional support is required

If you are in search of a little respite and change of scenery, Independence Australia's Bayside Villa could be exactly what you are looking for.

For bookings and/or further information please contact Independence Australia:
Ph: 1300 704 456
Email: communitysolutions@independenceaustralia.com



Dr Federick M. Maynard,
MD (Retired)

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Ask Dr. Maynard

Q. People in my post-polio support group say I need to see a 'polio doctor'. **What is a polio doctor?** Do you agree that polio survivors must see a physician with such a designation? **Do I need my old medical records?**

A. There is no official certification for a 'polio doctor'. I believe the most common use of this informal designation is for a physician with knowledge, experience and interest in evaluation and treatment of polio survivors.

Given the most common new disabling medical problems of polio survivors, physicians with expertise in neuromuscular disease management that includes the ability to recognize and treat chronic musculoskeletal pain and respiratory problems are ideal. The specialty background of these physicians is most commonly neurology, physical medicine & rehabilitation (physiatrist), orthopedics, pulmonary and family practice.

I am not of the opinion that every polio survivor must see a polio doctor. If a survivor is experiencing a series of new unexplainable and disabling symptoms and is unable to obtain satisfactory help, then I would encourage him/her to seek evaluation by a polio doctor/post-polio clinic. These physicians most commonly will provide consultation services to your primary care physician and may also provide continuing comprehensive follow-up of post-polio related problems.

Many survivors need a network of medical providers (orthopedist, pulmonologist, orthotist, physiatrist, neurologist, etc.) and may need help with coordination and communication among them. A primary care physician can fill this role, although many polio survivors do this function themselves, because they are sufficiently sophisticated with medical and rehabilitative issues.

There is no 'one size fits all' answer to your question. The question is better asked, "Are polio survivors' medical and rehabilitative needs being met by their current providers?" If not, then specialist consultations are appropriate. If survivors need a comprehensive evaluation of medical concerns and functional changes, then I think seeing a 'polio doctor' is invaluable.

A. Regarding the question about tracking down your medical records, they might be of interest, but of little real value to your physicians in making treatment decisions. To find an explanation for your muscle pain, seek an evaluation by a physician who familiar with post-polio syndrome, such as a local neurologist or physical medicine & rehabilitation specialist.

He/she should perform an EMG (electromyography) for two good reasons. First, it is the best test to establish that the muscles now having pain do show a pattern of electrical activity compatible with having remote (old) polio involvement; that is, they appear to have lost the typical number of motor nerve cells.

Second, the test will show if the nerve/muscle cell status is stable or unstable. This fact can guide your physicians and therapists in treating your muscle pain with exercise, including how much exercise and how concerned you or they need to be about over-exercising/overusing these painful muscles. •

News from Israel

continued from page 1

Now, disability support, nowhere near the level needed to deal with the increased needs of people with polio is provided largely by the National Insurance and seems to be dependent on a diagnosis. The existence of 'Post Polio Syndrome' is important in gaining benefits. A primary concern for this group is that the National Insurance

is not adequate to cover the cost of adaptations of vehicles and homes to accommodate chairs and scooters, or the upgrading of orthotics.

The group was interested to hear about the response to the epidemic in Victoria and expressed their frustration that such expertise existed but their doctors were unaware. Even as I described the premature reduction of polio services in Victoria in the early

1990s, when many of us needed greater support, the minimal service that remains contrasted favourably with their lack of polio specific services or specialists. The lack of appropriate response is the basis of their claim. According to the polio law, a special committee nominated by the ministry of health will decide upon the treatments that the polio survivors should take and all the other steps that will ease the life of the polio victim.

Good Thinking

by Dr Andrew Sinclair – Independence Australia Psychologist



Getting Mobilised!

Recently Mary-ann asked me to be involved in the up-coming Polio Day 2009.

Reading over the plan for the day I was struck by how many of the scheduled activities to 'try' are similar to what we recommend for clients experiencing depression. Loads of research shows that getting out there and doing activities like playing Bocce or practicing yoga can significantly reduce the length and severity of depression.

However, when depressed a person's motivation to 'try' can be a problem as one of the effects of depression is feeling immobilised. It's hard to push yourself to do the normal everyday activities, let alone add challenging new ones.

In addition, feeling immobilised is not just a symptom of depression it is also a cause. The less you do the more depressed you feel; and the more depressed you feel, the less you do. This process works like a negative spiral, encouraging us to do less, and prolonging depression and inactivity. A similar process may also affect people with the late effects of polio as activity becomes more and more challenging.

What about if the mind is willing but the body is weak?

Feelings of loss and depression are also not unusual if we find we are unable to perform tasks we used to enjoy. Those of you experiencing the late effects of Polio may be battling a loss of strength, function and ability. When faced with these losses you may feel helpless, depressed or immobilised. I imagine 'trying' new things is the last thing you feel like

doing. However, to get the benefits of activity on our mind, body and spirit we need to mobilise ourselves. If you are experiencing trouble with motivation, some techniques that work with depression may be helpful.

How do we push ourselves to higher levels of activity when we don't feel like it?

One widely used technique to re-energise and overcome lack of motivation is called 'activity scheduling'. The process is reasonably simple, with early steps involving monitoring your daily activities and later progressing to scheduling in advance increasing numbers of pleasurable activities.

Essentially you begin by **recording** your activities over the course of a week. After each hour you record the activity you undertook during that hour, the amount of pleasure you derived from that activity and your perceived sense of achievement given how tired or depressed you felt at the time. I find it's best to use a ten point scale from 1 (no pleasure/minimal sense of achievement) to 10 (significant pleasure/great sense of achievement). As an example you might attempt some weeding one day during the week you recorded your activity. On your record sheet you would detail



this activity and your ratings e.g. Tuesday 1pm – gardening (Pleasure 5, achievement 3).

This process allows you to record all your activities and may help you recognise when your life is out of balance. Too many boring, difficult activities will provide little emotional nourishment. Further, you will get little satisfaction from life if there are too few enjoyable activities you can master in your daily schedule. At the very least, the monitoring process will help you discover how much effort you are putting in. It's worth noting to yourself that the things you are doing are real achievements, given how you feel, physically and emotionally.

The next step is to begin **scheduling** pleasurable activities that you feel competent in. As the weeks go by you can increase these activities in a sustainable way. As you complete more and more pleasurable activities, you will begin feeling better and more energetic. Soon the negative feedback loop is replaced with a positive one. As you feel better, you have more energy and motivation to do more, which makes you feel even better. One last tip to improve motivation is to schedule activities with other people. The fear of letting them down will reduce the chance you will cancel and miss out on the positive benefits of the activity.

If you are struggling with motivation and would like some assistance to mobilise yourself before the 'try' day in October, please contact the Psychology Service for information and resources. I will also be attending Polio Day 2009 and am happy to chat with you about this topic or any other questions you have on the day. •

How and when we make the transition to greater use of mobility aids, and how we shift psychologically is another common concern we discussed. Although Ron and I have travelled often, this was our first trip overseas taking a wheelchair. It was both liberating to be able to keep pace with Ron but also challenging to learn how to negotiate our way around an unfamiliar environment that is not designed with wheelchairs in mind.

Adapted activities for the disabled seem better developed in Israel than in Australia. Haya is involved in wheelchair dancing of all sorts – salsa, folk and others. Yehuda has played basketball for many years. I had enjoyed free entry to museums and art galleries as a person with a disability. This seemed to me a great way to encourage people with disabilities, who may be discouraged by the difficulty of negotiating a chair or scooter, to public venues and events.

For me there was a sense of being an 'honoured guest' when I was informed that I did not need to pay the entrance fee. I would like to see this introduced in Australia. This inspiring group of polio survivors show that with preparation and tenacity it is possible to influence legislators even in such a difficult political environment. We thank our Israeli friends for their hospitality and look forward to hearing more positive news about their campaign. •

Polio Day 2009

Monday 12th October

**Darebin Community Arts & Entertainment Centre
Cnr St Georges Road & Bell Street, Preston**

Based on the wonderful format presented at the 2009 Post-Polio Wellness Retreat at Roosevelt Warm Springs, Georgia, USA, this Polio Day will introduce you to a range of experiences and activities addressing the overall **Body – Mind – Spirit** aspects of Health and Wellness. You may be interested in exploring seated Yoga, learning more about pain management, having a mini-massage, or trying out the latest scooters and wheelchairs. There will be something for everyone (see timetable opposite).

Polio Day is also a time to catch up with friends, enjoy lunch and refreshments, and view the displays. Please come along and help us celebrate Polio Day 2009!



BODY



MIND



SPIRIT

Details

VENUE	Darebin Community Arts Centre Cnr St Georges Road & Bell Street, Preston Melways Ref 30 E1
COST	\$10.00 per person – to be included with your returned application
PARKING	Free, on-site parking for 250 cars
PUBLIC TRANSPORT	Train Epping Line stopping at Bell Station Tram 11 From Collins Street to West Preston stopping at the corner of Miller Street and St Georges Road, Preston Tram 86 From Bourke Street to Bundoora stopping at the corner of Bell Street and Plenty Road, Preston

Booking Form

Please return the booking form opposite with payment to confirm your attendance by **Friday 2nd October** and/or refer any enquiries to:

Mary-ann Liethof













Polio Network Victoria – Independence Australia
208 Wellington Street, Collingwood, 3066

Ph: (03) 9418 0411
Mob: 0425 785 871
Fax: 1300 704 451
Email: polio@independenceaustralia.com


PROGRAM

10.30am	Registration / Refreshments in Foyer
11.00am	Housekeeping and Introduction of Independence Australia Rep and Polio Advisory Committee Chair
11.10am	Welcome from IA Rep and PAC Chair
11.15am	KEYNOTE SPEAKERS: Trying new things at the Post-Polio Wellness Retreat (Roosevelt Warm Springs, April 2009) <ul style="list-style-type: none"> • Shirley Glance, Convener, Bayside Polio Support Group • Fran Henke, Member, Mornington Peninsula Post Polio Support Group • Liz Telford, Member, Polio Advisory Committee
12.00pm	Stretch Break
12.10pm	‘Living with Polio in the 21st Century’ Conference summary <ul style="list-style-type: none"> • Mary-ann Liethof, Polio Network Victoria
12.40–1.40pm	Lunch / Social / Displays <ul style="list-style-type: none"> • Catch up with old and new friends • Watch PPS: <i>Shades of Grey</i> film • Polio Roll Call display • Variety of displays

Health and Wellness 'Try Day'

1.40–3.10pm	Health and Wellness Try Day Activities & Sessions		 BODY	 MIND	 SPIRIT
1.40 - 3.10pm	Pain Cause & Management Full 1½ hour interactive workshop	Dr Stephen de Graaff Medical Pain Specialist, Epworth Rehabilitation Dr Andrew Sinclair Health Psychologist, Independence Australia	½ Grevillea Room Seats 150		
1.40–3.10pm	Write Your Own Story Full 1½ hour interactive workshop	Katherine Ross Journalist and Editor	Studio Room Seats 70		
1.40–2.20pm or 2.30–3.10pm	Seated Yoga & Meditation 2 x 40 minute sessions	Trisha Jones Chiro Yoga	Waratah Room Seats 30		
1.40–2.20pm	Exercise Options 40 mins practical session	Simon Mathieson Physiotherapist, Polio Services Victoria	½ Grevillea Room Seats 150		
2.30–3.10pm	Learn to play Boccia 40 mins practical seated and adapted Bocce session	Bocce Victoria	½ Grevillea Room Seats 150		
1.40–3.10pm	Explore Mobility Aids & Equipment 1½ hour ongoing exploration	Mobility Plus	Foyer		
1.40–3.10pm	How to Maximise Independence 1½ hour ongoing discussion	Stephen Hughes Orthotist, Polio Services Victoria Margaret Petkoff Occupational Therapist, Polio Services Victoria	Foyer		
1.40–3.10pm	Introduction to the Internet 1½ hour ongoing session	TBA	Foyer		
1.40–3.10pm	Mini Seated Massage Sessions 15 mins ongoing sessions	Myotherapy Students Kangan Batman TAFE	Acacia Room Seats 120		
3.15–3.30pm	RETURN TO GREVILLEA ROOM FOR DOOR PRIZE DRAW & CONCLUSION				

BOOKING FORM

 Name/s 1. _____
please print 2. _____
3. _____
4. _____

Address _____

Phone/s (Day) _____
(Mob) _____

Email _____

Special dietary needs:

Coeliac Food Allergies/Intolerance:
please specify _____

Payment details

Enclosed is my cheque/money order for \$10.00 per person made payable to **Independence Australia** for \$ _____
or please debit my:

Visa MasterCard Expiry Date: _____ / _____

Card No. _____ Account Number: 30 09 1026

Name on Card _____

Signature _____ Amount \$ _____



RECEIPT

(will be handed out during registration)

Name _____

For: **Polio Day 2009** Amount: \$ _____

Knox-Yarra Ranges Polio Support Group



Members of the Knox-Yarra Ranges Polio Support Group shared breakfast with Peter Maldon from Boronia Rotary Club, on Sunday 19th July.

Peter presented the convenor, Joan Smith with a cheque for \$600 to assist with the publication of a book 'The Calliper Kids'. The group has compiled a collection of their life stories about living with polio and the new effects in their lives as they age. The book will be provided free to all medical practices, aged care providers and libraries in the area.

Further information is available from Joan Smith on 9756 6383. •



Polio Services Victoria 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

- September 9
- October 7, 21
- November 18
- December 2, 16

Regional

- 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
 Noel Robertson ph: 5332 3172
 Margaret Tuddenham ph: 5335 6702
 email: mt@netconnect.com.au
 Coral Rumler ph: 5342 0629

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: polioeast@gmail.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
 Winnie Teo ph: 0408 599 775
 Neil Winter ph: 5241 9591
 email: teo_express@yahoo.com.au

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: ddlloyd@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	Tuesday 27 October