



Volume 3, Issue 2

Polio Oz News

July 2013 – Winter Edition

The 2013 "We're Still Here!" Pre-Election Campaign

by Mary-ann Liethof
Editor

They say that timing is everything, and Polio Australia certainly picked an historical day to visit Parliament House! Alas, on Wednesday the 26th of June, the corridors were not abuzz with word that the post-polio campaigners were there - rather that the country was about to have a leadership change on that very day, of all days!

And if that wasn't problematic enough, our President and Campaign Leader, Dr John Tierney, and Vice President, Gillian Thomas, were both suffering with symptoms akin to Spanish 'Flu, so were not feeling as 'bright' as they could have.

However, in true polio style, they soldiered on!

As did 37 [Campaign Heroes](#) made up of 18 polio survivors and 19 family members and friends who had made the trek to Parliament House, Canberra, which is an historical day in its own right.

They were made up of 6 ACT-based Campaign Heroes, 20 from New South Wales, 3 from Queensland, 6 from Victoria, and 1 who came all the way from Western Australia.

[The day commenced](#) with a Morning Tea Forum with a bipartisan panel of 3 Senators discussing the National Disability Insurance Scheme - now named "[DisabilityCare Australia](#)" - and 'where to from

here' for 65 years and older polio survivors. Senators [Mitch Fifield](#) (Liberal), [Rachel Siewert](#) (Greens), and [Claire Moore](#) (Australian Labor Party) proffered a range of opinions, but all recognised that the [65 year cut off](#) for Program eligibility was unfair for a large percentage of Australians, but that there was still the possibility for changes to be made over the next 6 years it will take for "[DisabilityCare Australia](#)" to roll out across Australia.

Following the Morning Tea Forum, most of the Campaign Heroes met with 9 parliamentarians who offered their time to listen to the issues affecting Australia's polio survivors.

Cont'd P 4



2013 "We're Still Here!" Campaign Heroes

National Patron: Dr John Tierney, PhD, OAM

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Inside this issue:

"We're Still Here!" Pre-Election Campaign	1
DisabilityCare Australia	7
PA Questions Bill Gates	8
Thanks Neil!	9
Supporting Polio Australia	10
Health & Wellness Retreat	12
Touched by Polio	19
Walk With Me	20
Polio Network Victoria	21
My Story	22
My Treatment in Hobart	24
Access All Areas	25
Reading	26
Fears Over Modern Polio	28
Polio Alerts	30
Polio This Week	30

From the President

Dr John Tierney
President

Fellow polio survivors, the last few months have been very busy at Polio Australia, culminating in our most effective visit yet to Canberra, judging by the outcomes of the work of the delegation to date. I would particularly like to thank our 37 campaign heroes who trekked to Canberra in the dead of winter, at their own expense, to join in the lobbying effort which included their own meetings in the private offices of the members and senators. A special thanks to Mary-ann who displayed her usual dedication and flair in bringing everything together on the day.

Our delegation was highly visible around the Parliament and in Question Time in our "We're Still Here!" T-shirts. We were there when the Government changed Prime Ministers, so a very dramatic day all round. Mary-ann has put photos and information about the lobbying day elsewhere in the newsletter and Gillian (as Webmaster) has been working on Polio Australia's "We're Still Here" website.

Cont'd P 3

From the Editor

Mary-ann Liethof
Editor

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Well, I certainly have a bumper edition for you to browse through this month. This is largely due to the fact that I was unable to get any e-news together last month with so much energy going into organising the campaign, and the Retreat before that... As the only paid staff member already doing the 'impossible', performing miracles just takes that little bit longer!

In this edition of "Polio Oz News", you will see that Polio Australia has certainly been keeping busy, as have all the 'Retreaters' and 'Campaign Heroes'.

We have also included the inspiring story of Elizabeth Edmondson (P 22), a Western Australian Paralympian who joined in on both the aforementioned activities.

Most of us now know that DisabilityCare Australia (*the National Disability Insurance Scheme*) was launched in 4 regions on the 1st of July, and you can read more about that on P 7.

On P 8 you can read how our Vice President, Gillian Thomas, was invited to a special edition of Q&A featuring Bill Gates.

On P 21 you can read the next in our series on state based networks - Polio Network Victoria.

And much, much more! So just take your time and enjoy! 🌟

**Change will not come
if we wait for some
other person or some
other time.
We are the ones we've
been waiting for.
We are the change
that we seek.**

~ Barack Obama ~

From the President (Cont'd)

On this trip, the Parliament has moved from just listening to what we have had to say, to actually doing something. Thanks to the excellent and comprehensive handout that Mary-ann put together, the penny stated to drop with a number of MPs. We asked Members and Senators to put a story and photos in their electorate newsletters which go out to their 80,000 constituents. We also asked them to publicise the Australian Polio Register and to add in the link to the Polio Australia website. Quite a number have promised to do this.

We now have 65 *Parliamentary Friends of Polio Survivors*. These Members and Senators have either spoken to our delegation, attended one of our functions, or spoken about the needs of polio survivors in the Parliament. Also after this visit, two of our Parliamentary Patrons have had follow up meetings with the Health Minister and the Shadow Health Minister on the needs of polio survivors. This is pure gold.

I would like to single out two of our Federal Parliamentary Patrons for special mention. Again, Mark Coulton MP (NSW), National Party Chief Whip, was a tower of strength in helping with arrangements on the day. The Hon Greg Hunt MP (Lib, Victoria), Shadow Minister for the Environment, helped spread the message in a speech to the Parliament, where he called on MPs to take a bipartisan approach to meeting the needs of polio survivors.

Our central message to the MPs was that the "one size fits all" competitive grant funding model does not work for meeting the needs of polio survivors. **We need specific purpose funding for programs and publicity that will lead to polio survivors better managing their own condition.** While we are all waiting for government funding to arrive, we will have to continue to raise it ourselves.

Our next big happening that you can all participate in is the "Walk with Me" events, details of which can be seen on P 18 of this newsletter. Last year we joined in as a trial and found that Fran Henke and I could raise \$3,770 dollars between us. Imagine what one hundred of us could raise! It only involves a short walk on a stick (or in a wheelchair) and we encourage participants to bring family and friends with them. It is not physically onerous and really a lot of fun. Try and find 10 to 50 of your family and friends to sponsor your walk and between us we can help raise a lot of money for our cause.

Take care,

John

Dr John Tierney OAM
President and National Patron
Polio Australia 🇦🇺



Campaigners pinning their leaves to the "Polio Family Tree"



John Tierney (left) leading some of the campaigners through Parliament corridors



(l-r) David Luck, Alan Tudge MP, and Joan Smith

"We're Still Here!" Pre-Election Campaign (Cont'd)

Everyone was provided with a specific, budgeted, Proposal on what Polio Australia is asking from the government.

In a follow-up letter to all the parliamentarians Polio Australia Campaigners meet with in Canberra, thanking them for their time, the following comments were made:

"Polio Australia believes that if bi-partisan support can be agreed upon for the Australian government to commit AU\$130 million (see P 8) to fund the very worthy cause of polio eradication, dedicated funding must also be made available to support our own polio survivors – understanding that this support is really only required for a limited time.

Unlike many other chronic conditions, it needs to be reiterated that Polio Australia is the only organisation providing services for polio survivors, yet there appears to be no mechanism for these services to be funded through federal government.

In 2011, Polio Australia unsuccessfully applied for two of the Department of Health and Ageing's (DoHA) Flexible Funding grants, although no further grants have been released since this time. Unfortunately, the Late Effects of Polio do not fit into any of DoHA's programs or initiatives, so there are no other appropriate tender submissions available to apply for."

Polio Australia thanks the following parliamentarians and Advisors for their time in Canberra:

Morning Tea Forum Panel



(l - r) Senator Mitch Fifield, Senator Rachel Siewert, Senator Claire Moore

Parliamentary Patrons

[Mark Coulton MP](#) (National, NSW)

[Jill Hall MP](#) (Australian Labor Party, NSW)

[The Hon Greg Hunt MP](#) (Liberal, Vic)

[Senator Rachel Siewert](#) (Greens, WA)

(newly invited after unsuccessfully proposing amendments to the NDIS Bill to include 65 yo)

Parliamentarians Campaigners Met With

(in addition to Parliamentary Patrons)

[The Hon Bronwyn Bishop MP](#) (Lib, NSW)

[The Hon Russell Broadbent MP](#) (Lib, Vic)

Tom Fleming, Senior Advisor to [the Hon Peter Dutton MP](#) (Lib, Qld)

[The Hon Joel Fitzgibbon MP](#) (ALP, NSW)

[Josh Frydenberg MP](#) (Lib, Vic)

[Michael Keenan MP](#) (Lib, WA)

[The Hon Richard Marles MP](#) (ALP, Vic)

Sandi Gatt, Advisor to [Senator the Hon Jan McLucas](#) (ALP, Qld)

[Scott Morrison MP](#) (ALP, NSW)

[The Hon Amanda Rishworth MP](#) (ALP, SA)



"We're Still Here!" Pre-Election Campaign (Cont'd)

The Hon Bruce Scott MP (Nat, Qld)
Alan Tudge MP (Lib, Vic)
Senator Anne Urquhart (ALP, Tas)

Additional Parliamentarians Who Attended Morning Tea

Karen Andrews MP (Lib, Qld)
Anna Burke MP (ALP, Vic)
Steve Georganas MP (ALP, SA)
Philip Ruddock MP (Lib, NSW)
Kelvin Thomson MP (ALP, Vic)

motif with the words **"I am a polio survivor and I need polio-specific services NOW!"**.

A few of these T-shirts are left over in Large, X-Large, and 2X-Large, and can be purchased from Polio Australia for \$25.00 each (which was the price Polio Australia paid for them) plus \$5.00 postage and handling. Email [Mary-ann](#) for availability and payment details.

There was a flurry of additional [stories](#) posted onto the campaign-specific "[We're Still Here!](#)" website created by the talented Gillian Thomas leading up to the day, and any media stories have also been linked. Polio Australia intends to use this website for additional stories, so keep them coming in.

The following emails from Campaigners provide their reflections on the day:

From Nola and John Buck (NSW)

"John and I really enjoyed the day and for me it was a success. It was obviously a very busy day in Parliament, yet the Members found time to come and see us, and surely that commitment from them is due to all the lobbying you, Gillian and John have done on behalf of Polio Australia. I was really impressed with Claire Moore saying that the Committee is aware that the decision to exclude people with disability from DisabilityCare when it is fully functional will have to be re-thought. This sentiment was also expressed by the Human Rights Commission President [Professor Gillian Triggs] on ABC Lateline on Thursday night. I feel all your hard work is starting to pay off and as Greg Hunt said, we need to continue



During this visit we also wanted to acknowledge the wider circle of people who are "Still Here!" with our polio survivors. As such, all Campaign Heroes were issued with an orange card 'leaf' to hang on our "Polio Family Tree", as well as T-shirts depicting the leaf

"We're Still Here!" Pre-Election Campaign (Cont'd)

to make a lot of noise. I'm not too sure about success in relation to funding for Polio Australia, but hopefully one of the funding avenues mentioned by one of the MPs will give us an opportunity to obtain funding."

From Rohan Clark (ACT)

"Congratulations on a wonderful event yesterday. Your organisation and preparation were terrific. The Polio Family Tree was a great idea and looked great. And it was practical – portable and effective! The range of speakers and attendees you had arranged were just fantastic. We must continue to be a "squeaky wheel", as we must be to get our case heard and acted upon, and your contribution to this is truly outstanding.

Your background work contained in the booklet, "Proposal to Support Australia's Polio Survivors", June 2013, was just fantastic. It was clearly a lot of work, but it was worth it and it was very well done indeed.

The day went as well as it could possibly have gone. It takes skill to arrange something months in advance on the same day as a political killing! Seriously, the pollios may have been somewhat distracted, but we still got our message across, and we must continue to do it. I am an optimist, and believe

that funding will be found from somewhere for you to continue in your role – no doubt you are busy on that front as well."

I have been asked by several people if I think this campaign was 'successful'. All I can say is that, in spite of the challenge of competing with a leadership change on the day, we had significant interest from a number of additional parliamentarians we haven't met before. I don't think we should ever underestimate the power you have as voters. For example, it was amazing to see the Speaker for the House of Representatives, Anna Burke, attending Morning Tea, thanks to a very staunch advocate in her electorate (who was unable to attend Canberra herself).

However, if 'success' is measured by a promise that Polio Australia will receive funding, then the answer is "not yet" . . . Unfortunately, our lobbying efforts are a bit like water dripping on a rock - eventually the constant drips wear it down – we hope! After all, it's only been 25 years since we first started talking about the problems we've been having with the late effects of polio!

Another way to look at the success of this campaign is in the opportunity to share our stories and experiences with a number of MPs and Senators, and with each other.

Polio survivors and their families came from all over Australia to unite for this campaign and to make our voices heard – not just for ourselves, but for the hundreds of thousands of other polio survivors out there. Remember, we are all part of a much bigger picture and, as Rohan said, it's the squeaky wheel that gets the oil!

So, a special "thank you" goes to all the Campaign Heroes who made the significant physical and financial effort to join with Polio Australia, and with each other, to make this campaign worthwhile.

What now, you might ask? Well, first we have to get through the federal election so we can see who's left standing . . . We know we have bi-partisan support, so we hope that our campaigning has made enough of an impression that when the Members and Senators return to parliament, we can take up where we left off and continue to make progress.

And remember, **YOU CAN HELP!** Let your local federal Member know you are a polio survivor living in his/her electorate (*otherwise they won't see the late effects of polio as something they need to think about*), and send them a link to Polio Australia's [Proposal](#) so they know exactly what the issues are.

Onwards and upwards! 🌟



Campaigners with Michael Keenan MP



Greg Hunt MP



Merle Thompson with Joel Fitzgibbon MP

DisabilityCare Australia



On 1 July 2013, [DisabilityCare Australia](#) commenced in Tasmania for young people aged 15-24, in South Australia for children aged 0-14, and in the Barwon area of Victoria and the Hunter area in NSW for people up to age 65.

From 1 July 2014, DisabilityCare Australia will commence across the ACT, and the Barkly region of Northern Territory. Roll out of the full scheme in these states and territories, as well as Queensland, will commence progressively from July 2016.

If you are a person with disability and you meet the access requirements you can become a participant in the scheme. As a participant, you will be able to access DisabilityCare Australia community linkages and individualised planning processes to identify the reasonable and necessary supports you need to enable you to

achieve your goals. To get an idea about whether you meet the access requirements, you can use [My Access Checker](#).

If you do not meet the [access requirements](#), and you live in a [launch site](#), DisabilityCare Australia may be able to provide you with information about other supports that could be of benefit to you and assist in referral to these.

DisabilityCare Australia will also work in close partnership with local communities to improve inclusion and people with disability. The agency will also look at fostering innovation, research and best practice to better support people with disability. In building awareness of disability across the general community we can address the things that can make a difference to everyday life for people with a disability, their families and carers. ●

Launching DisabilityCare Australia – A Cautionary Tale



The following is an excerpt from a longer article written by Tricia Malowney for ProBono Australia News

- Source: www.probonoaustralia.com.au/news - 4 July 2013

DisabilityCare Australia is here but let's not think this is all done now – nothing will change until families, politicians, the service sector and Australians with disabilities understand that we are equal partners, says systemic advocate for inclusive practices, Tricia Malowney.

"On Monday, I was fortunate to be able to attend the launch of DisabilityCare Australia at the Geelong office, followed by a reception at the Geelong Town Hall. Let me say that the first event was brilliant. It was attended by many Australians with disabilities, our families and supporters, members of the disability sector and bureaucrats and politicians who had all worked side by side at the local, state and federal level to ensure that DisabilityCare Australia became a reality.

So all of us were in fine form as we travelled to the Town Hall to continue what we thought was to be a reception to celebrate a new era in how Australians with disabilities were able to finally exercise their citizenship rights, be included in the community, and change the way we were to be treated in the future.

How wrong could we be! The event at the Town Hall was awful – it was overcrowded with not enough seating. Australians with disabilities who were not able to find their way to the front of the room were left looking at the backs of those who stood in front of us. I was lucky enough to find a seat on a table, until I was bumped so the food could be put out." . . Continue reading full article [here](#). ●

Polio Australia Questions Bill Gates

On 28th May Polio Australia was grateful to have the opportunity to be in the 900 strong audience of a special episode of the ABC TV program [Q&A – An Audience with Bill Gates](#).

What was even more exciting for Polio Australia was the chance to ask a question of Mr Gates. [Watch this video](#) to see Gillian Thomas (*pictured right top*), Vice President of Polio Australia, ask Mr Gates (*pictured right bottom*) for strategies to “get governments to shoulder their responsibility and fund essential post-polio services”.

The video runs for 3 mins 13 seconds, but if you are unable to view the video, you download the transcript [here](#).

Of course, Polio Australia is well aware of Mr Gates’ specific interest in and commitment to eradicating polio in developing countries, and we are under no illusion that he would be a contributor to Australia’s polio survivors. However, the question was actually aimed at our government, and appeared on national television, so that’s got to count for something! 🌟

- Ed



Further Australian Support for Polio Eradication

Source: [Joint Media Release](#) - 28 May 2013
Prime Minister and Minister for Foreign Affairs

Prime Minister Julia Gillard and Foreign Minister Bob Carr today announced further funding to help eradicate polio – a debilitating disease that continues to strike the world’s most vulnerable people, especially children.

Australia will provide \$80 million over four years from 2015 to 2018 to help finish the job and achieve worldwide polio eradication.

This contribution follows a \$50 million commitment to the Global Polio Eradication Initiative from 2011 to 2014 announced by the Prime Minister at the Commonwealth Heads of Government Meeting in Perth in October 2011.

The Prime Minister and the Foreign Minister applauded the leadership shown by the Bill and Melinda Gates Foundation, the World Health Organization, UNICEF and Rotary International on polio. The Gates Foundation is contributing US\$1.8 billion for *the Polio Endgame Strategic Plan 2013 - 2018*, which is one-third of the total budget.

Australia has a proud history of support for polio

eradication. From 1912 to 1972, more than 30,000 cases of paralytic poliomyelitis were reported in Australia, and a number of polio survivors in Australia today still live with the pain and debilitation of post-polio syndrome.

It was Australia’s Sir Clem Renouf who, as President of Rotary International in 1978 and 1979, led the international campaign to vaccinate every child against polio. As a result of these early efforts by Rotary, the global community came together in 1988 to launch the Global Polio Eradication Initiative.

Since 1988, there has been a reduction in the number of polio cases by 99.9 per cent. Following the certification of India as polio-free in 2012, polio remains endemic in only Afghanistan, Pakistan and Nigeria. The world now has polio eradication within its reach. This would be the second disease to be eradicated globally after small pox and a major victory for international aid and public health.

The new contribution brings Australia’s total commitment to polio eradication to over \$130 million. Our aim is to help eradicate polio and strengthen routine immunisation. 🌟

Thanks Neil!



(l-r) Bev, Neil and Gail


Neil von Schill was a key member of Polio Australia's 'team' until he suffered a series of strokes in 2011 which affected both his mobility and speech. Neil is currently living in a residential care facility in Albury, New South Wales.

To thank Neil for his years of committed service to both Polio NSW and Polio Australia, the Committee of Management decided to present Neil with a plaque acknowledging his contribution.

Margaret Bennie, long-time member of the Albury Polio Support Group which Neil founded, was asked to make this presentation on behalf of Polio Australia. She wrote the following comments regarding the presentation:

"Neil's wife, Gail, suggested that morning is the best time for Neil as by lunch time he is rather worn out. So I went I up there before we went out to lunch. He was absolutely delighted and Gail was so pleased that Neil even smiled for the picture. Gail and her daughter, Bev, came out to lunch with the rest of our group.

Neil has been a mentor and friend for many years and is dearly missed by us all when we meet. We wish him and his family all the best.

It was a rather emotional day for us all and we would like to thank Polio Australia very much." 

- Ed

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Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 January to 30 June, 2013:

Hall of Fame (*\$1,000 plus*)

Name	Donations - General
Jill Pickering	\$28,000.00
Monique Liethof	\$5,000.00
John Tierney	\$4,830.00
Bruce Livett	\$2,500.00
Polio SA	\$1,550.00
Michael Evans	\$1,000.00
	\$42,880.00

Significant Donations (*up to \$1,000*)

Donation - General	
Mary Burbidge	Donations in memory of Eileen Meldrum
Paul Carlin	David Miller
J Chapman	T & J Pollock
H Doyle	Prospect-Blair Athol Lions Club
Elizabeth Edmondson	Margaret Reynolds
Carol Haider	Beryl Rigby
Lyndall Hendrickson	Douglas Ryan
Fran Henke	Len Sheehan
JMYF Enterprises Pty Ltd	C G Smith
Margaret Kinsella	Barry & Carol Squires
Knox-Yarra Ranges Post-Polio Support Group	Michelle Stonehouse
Stan Kosmala	The Better Image Australia
Lyn Lillecrapp	and a Number of Anonymous Donations
Total	
\$4,744.40	

Fundraising Campaigns Patrons Circle and Rotary Clubs of Australia

Name	Donations - Patron's Circle
Patron's Circle - Dr Ata Eshragi	\$10,000.00
Patron's Circle - Andrew Buchanan	\$1,000.00
	\$11,000.00

Name	Donations - Rotary
Rotary Club of Parramatta City	\$1,000.00
Rotary Club of Parramatta	\$500.00
Rotary Club of Warrandyte Donvale	\$250.00
	\$1,750.00

Making Polio Australia Work

Become a Friend – Invest in Polio Australia and Make a Difference

Please invest in Polio Australia's work to help ensure that all polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.

Polio Australia is endorsed by the Australian Taxation Office as a Health Promotion Charity and a Deductible Gift Recipient making all Australian donations over \$2 tax deductible. Polio Australia will issue an official receipt for all donations received.

Your Donation can be made via any of the following methods:

Cheque

Please make cheques out to Polio Australia Inc and post to PO Box 500, Kew East, Vic, 3102. To ensure your donation is correctly credited please click [here](#) to download, complete and then forward the donation form with your cheque.

Electronic Funds Transfer

Bank: Westpac
Branch: Parramatta, NSW
BSB: 032-078
Account Number: 555766
Account Name: Polio Australia Incorporated

To ensure your donation is correctly credited please click [here](#) to email your EFT transaction details to Polio Australia.

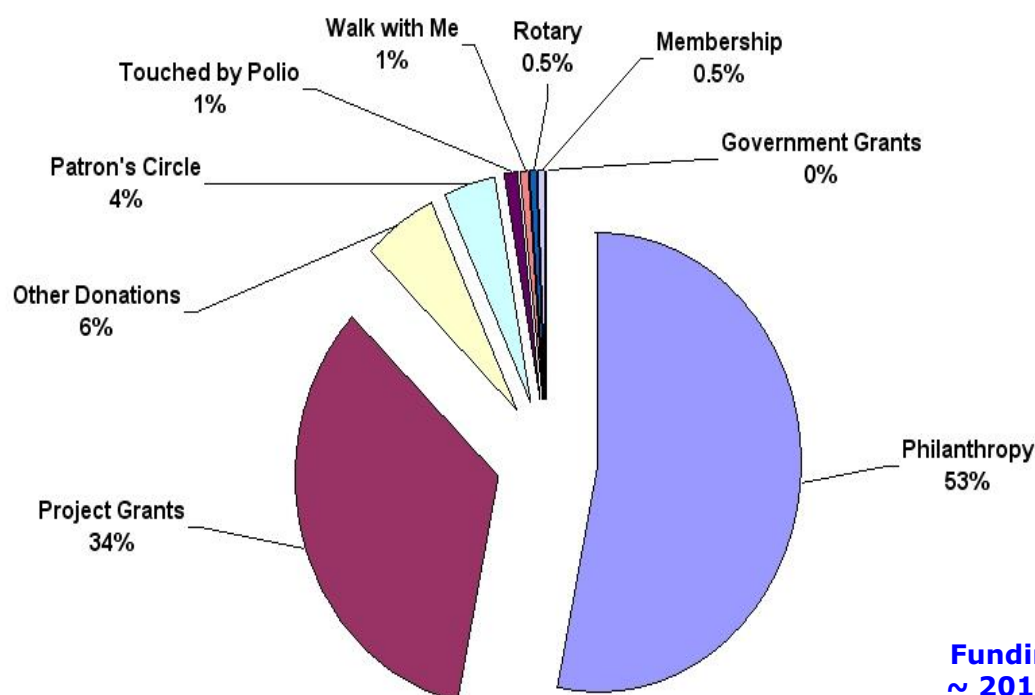
Credit Card or PayPal

Your credit card donation is securely processed through PayPal on behalf of Polio Australia. You do not need to have your own PayPal account. Simply follow the links on [this page](#).

Bequest

Include a specific bequest to benefit Polio Australia in your Will. Consider making a bequest to Polio Australia and determine the type of bequest which best suits your circumstances and wishes. Check [here](#) for details.

Thank you for investing in us to make a difference – every donation helps polio survivors



**Funding Sources
~ 2010 to date ~**

Polio Health and Wellness Retreat: 18th-21st April 2013



According to feedback received, we are very pleased to report that Polio Australia's [4th Annual Polio Health and Wellness Retreat](#) was yet another unmitigated success, thanks to the 70 participants who made their way to the Stamford Grand in Glenelg, South Australia, and the wonderfully generous efforts of the [40 session presenters](#), most of whom provided their services pro-bono. Many participants were also able to take advantage of the 2 massage therapists, Sharon and George, who were onsite for Friday and Saturday.

This was the most expensive Retreat we have held to date - primarily because we found it very difficult to find an accessible venue in a pleasant environment, which could accommodate 70 participants, in sufficient space, close to Adelaide. There were still a number of 'challenges' with regards to accessibility (showers-over-bath in standard rooms) which necessitated the hiring of additional bathroom aids. Paradoxically, Polio Australia received less philanthropic funding than in previous years.

Whilst the Stamford Grand did provide sponsorship in the form of a deduction on their regular pricing structure, it is an expensive hotel right on the beach . . .

However, we do wish to warmly thank The Marian & EH Flack Trust, as well as GlaxoSmithKline, for their ongoing and generous support for these Retreats.

Additionally, we give thanks to a few Retreat participants who followed up with various sized donations to Polio Australia. All contributions were very much appreciated.

This year I was also delighted to have 2 hard working volunteers helping out, Vivienne Maxwell and Alex Daniel. Lee O'Connell, Physiotherapist at MS Australia and Lecturer at University of SA, approached me to discuss the possibility of U of SA students undertaking a Project based on the Retreat. Of course, I readily agreed. So in 2012, Lee recruited and supervised Vivienne and Alex, who were then completing their fourth year in Physiotherapy.

Under my direction, Vivienne and Alex surveyed the needs of PolioSA members in relation to the 2013 Retreat, before exploring potential venues, session presenters, and funding sources, resulting in the production of a substantial report. Vivienne and Alex proved to be quick and astute workers leading up to the Retreat, and willing and able assistants for the weekend activities, where they were able to realise all their efforts. Having them there certainly helped reduce my stress levels! A great example of the future of our allied health therapists! 🌟

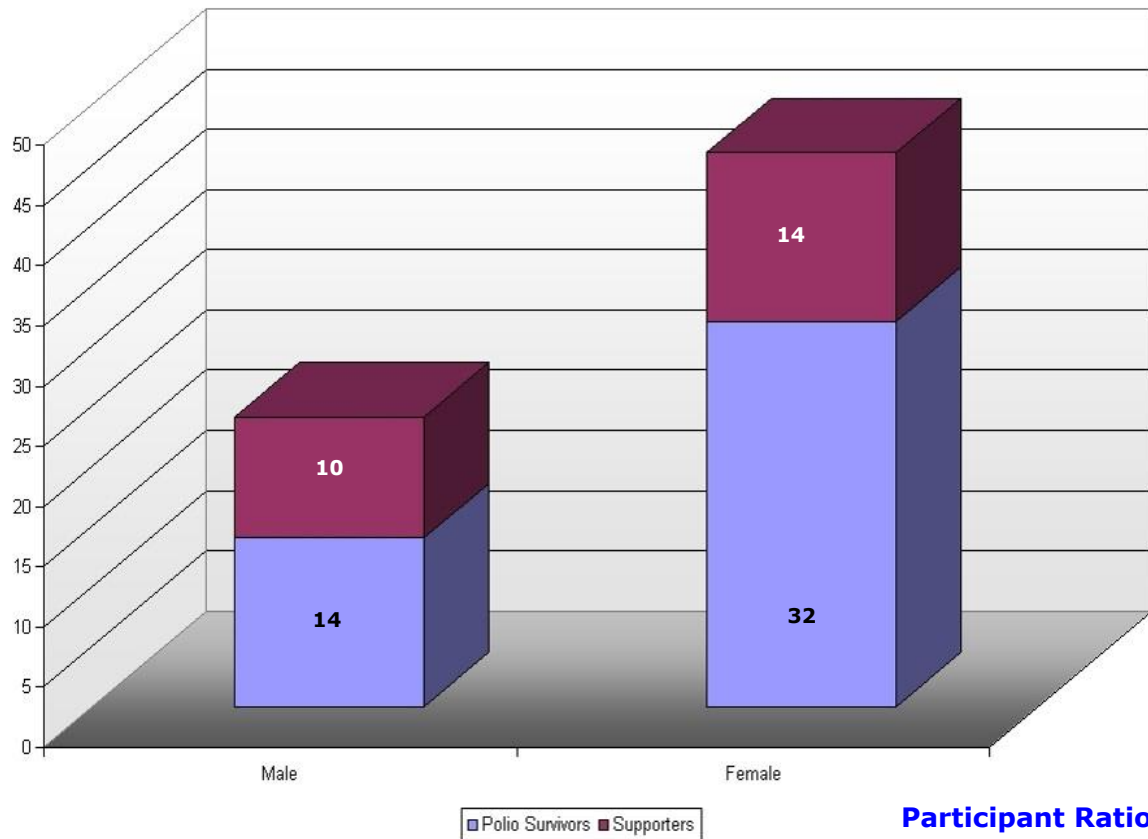
- Ed



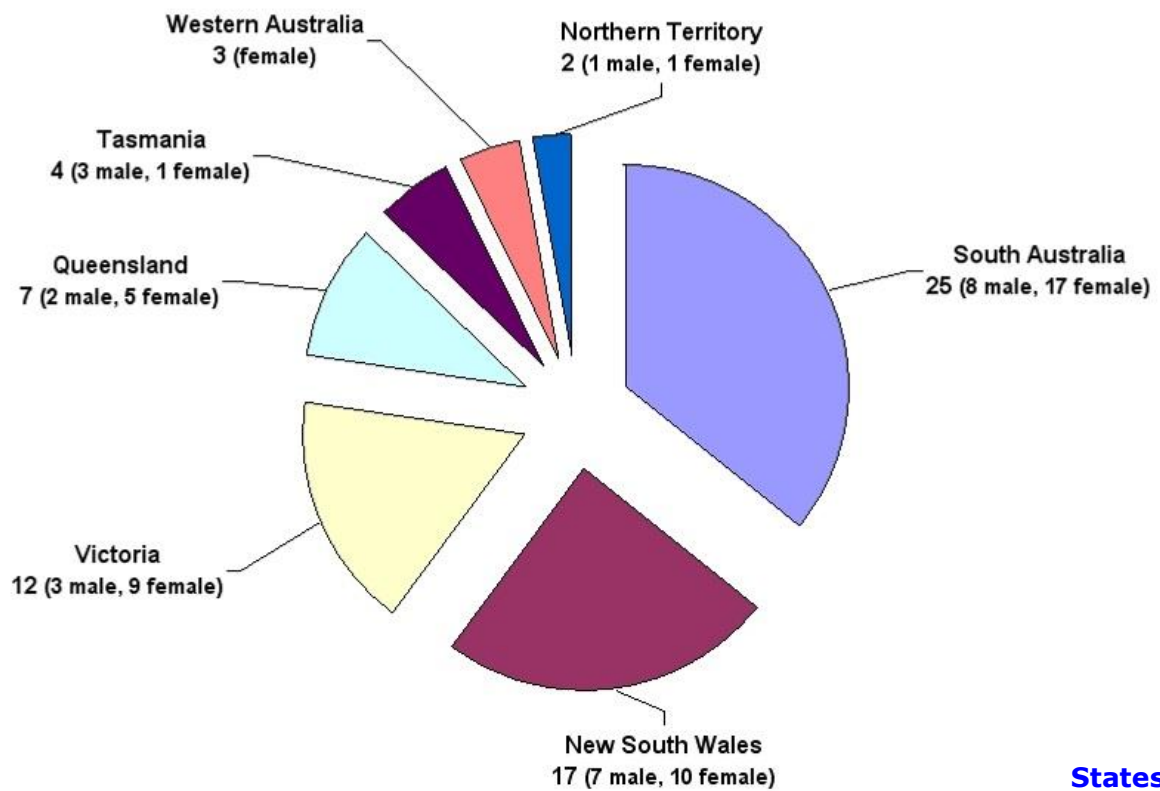
(l-r) Alex Daniel and Vivienne Maxwell

Polio Health and Wellness Retreat (Cont'd)

For those who like statistics, the 70 participants were made up of:

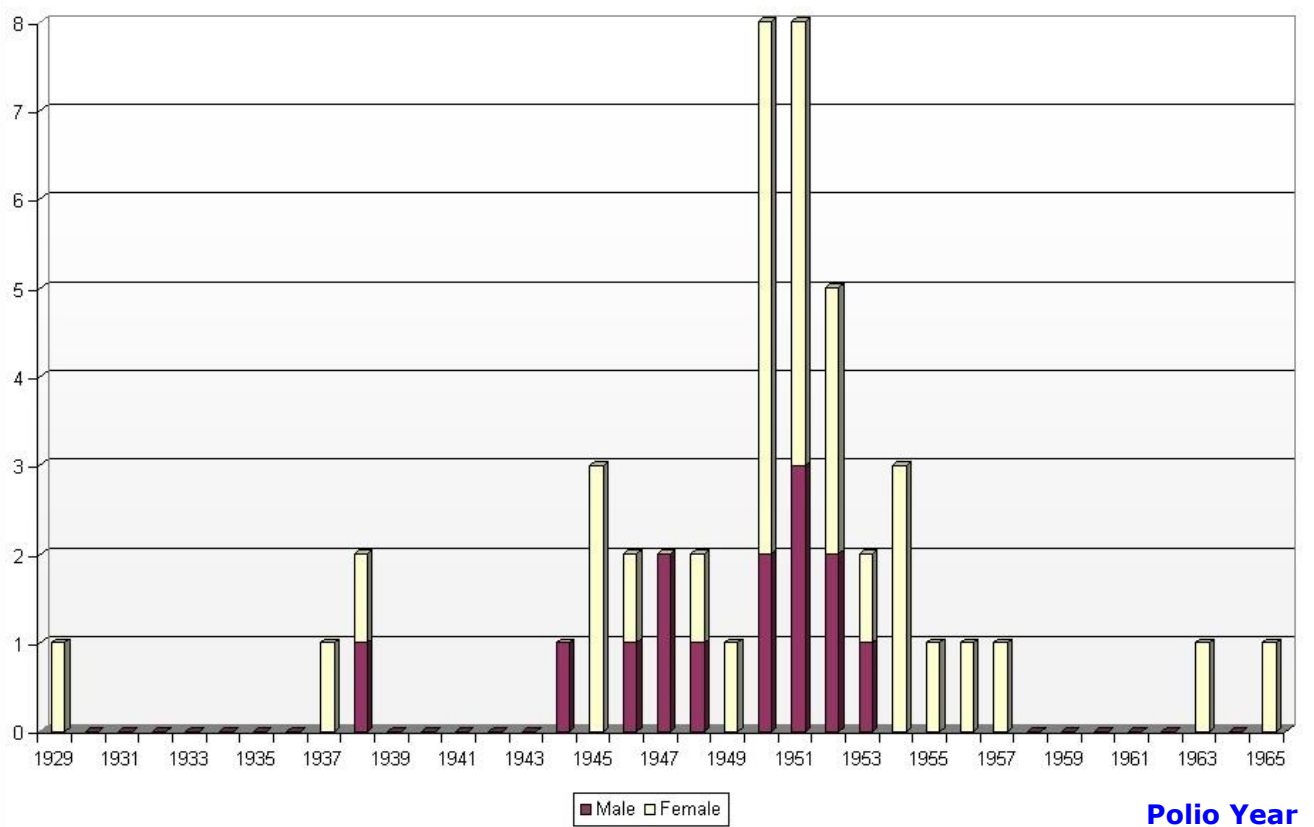
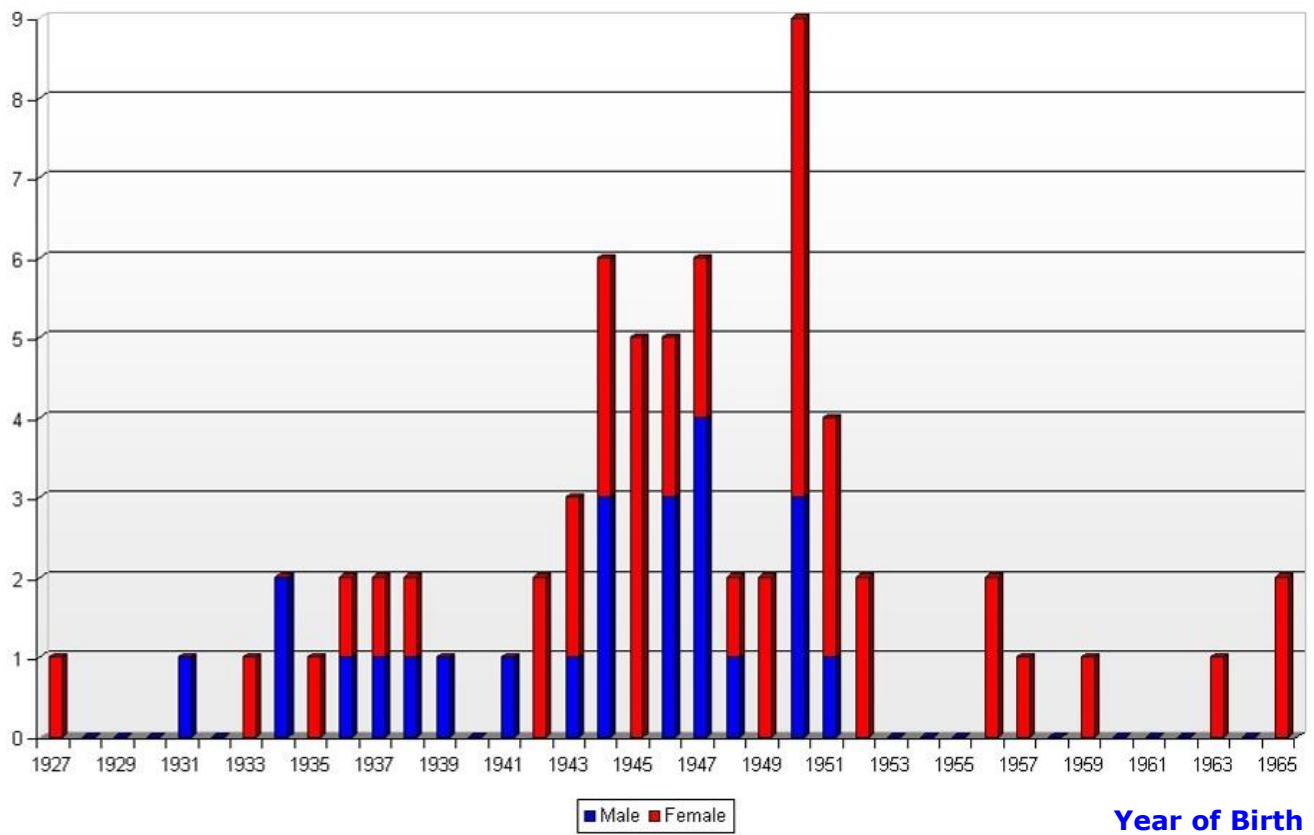


Participant Ratio



States

Polio Health and Wellness Retreat (Cont'd)



Polio Health and Wellness Retreat (Cont'd)

Reflections on the Retreat



by **Sylvie Cleret & Marc Adams**, Port Elliot, SA

What a fabulous 3 days. Our feet still haven't touched the ground.

Sylvie and I arrived at the Stamford Hotel on the Thursday afternoon and were seamlessly registered and directed to our lovely room overlooking the Glenelg Pier. The rest of the afternoon was spent exploring the beach and the local shopping precinct.

Thursday evening, everyone gathered for a lovely meal; to meet the other delegates; to hear Dr John Tierny, Gillian Thomas and The Hon. Steve Georganas; and to hear the ever present and effervescent Mary-ann Liethof. A delightful way to start the retreat.

Many choices of sessions were offered to the delegates; we all had to choose sessions prior to attending the retreat and this ensured that a maximum of 20 could attend each session apart from the plenaries which were open to everyone first thing each the morning.

The plenary on Friday morning introduced Ann Buchan, a "Neurophysiotherapist" from

Unley Physiotherapy. Ann explained various diseases that have similar symptoms to PPS; some statistics on polio people; various health issues of polios; discussed pain and its management; reflected on the loss of motor neurons and the possibility of other neurons making new pathways to overcome the lost pathways; and also touched on gentle exercise compared to strenuous exercise stressing the adage "Conserve to Preserve".

The next session for the morning was "Pain and Fatigue Management" by Dr Nigel Quadros, director of Rehabilitation Services at the Queen Elizabeth Hospital. Dr Nigel opened up a general discussion on central and specific pain, providing comment on various pharmaceuticals (mainstream and alternative). He then went into management of PPS, together with some of the other conditions that affect PPS such as carrying too much weight, etc.

Dr Nigel advocated "some" exercise by everyone even if it was only stretching, but keep to only a third of our maximum ability. The endorphins created by exercise bring about a "feel good" situation. He advocated soft massages, neuro-physiotherapy and advised that if a patient was at the stage where referral was needed to a "Pain Clinic" in Adelaide then there was up to a two year waiting list.

He also believes that the term Post Polio Syndrome should be replaced with "The Late Effects of Polio", a term not agreed with by everyone.

Friday afternoon brought Adam Holden, Orthotist from "Orthotics Prosthetics South Australia" which is part of Repatriation General Hospital. His topic of "To brace or not to brace" was a great success as people looked at and discussed various braces and orthotics and compared them to their own as well as their experiences.

Adam's theme was to increase quality of life, safe mobility and preservation of existing musculature/joints as well as providing optimal function with minimal inconvenience.

The next session on Friday was "Understanding Aged Care in SA" by Lyndal Gerrard from "Access 2 Home Care". Lyndal discussed how home care and its access are about to change in that the various services are about to be centralised. Lyndal provided some contact numbers and advice and gave an indication how people are assessed currently for the various services.

The option after the evening meal was a movie "The Sessions" or free time. Whilst many saw the movie we opted for free time in order to absorb the daily events.

Saturday morning started with a buzz as we were treated to an address from Susan Hillier, Associate Professor of Neuroscience and Rehabilitation from the University of South Australia. Her topic was "Neuroplasticity". Have you heard about it? We hadn't. It means the brain is capable of change. It underpins the way we learn and the way we

Polio Health and Wellness Retreat (Cont'd)

recover from brain trauma as well as how the brain processes chronic pain. Not only was the talk stimulating it was informative and positive.

Susan's theme was to get out there and do as much as you can, taking into mind fatigue, ability, etc. She advocated that we should be positive and not scared to do things, that we should pursue mental stimulation, not lock ourselves away but create a purpose in our life.

Next session for the morning was "Mindfulness" by Georgie Davidson. What a fabulous follow up from the previous session. Georgie has been a professional musculoskeletal physiotherapist and yoga teacher who brings a holistic approach to health care.

By bringing to mind the present moment, the taste, the look, the feel, we can learn to appreciate life as it is now instead of stressing over the past that we can't change, nor control our future. By appreciating the now we can appreciate ourselves and the world we live in.

The first session for the afternoon was "Partnering Polio" a session for the partners of polios. This session was run by Graeme Smith, the partner of Joan Smith, one of the polios. He opened up the group with a "tell your story and experience" from each member. This brought forth many strategies and coping methods and certainly showed everyone areas where they had to let go as well as how to introduce new ideas. Communication and negotiation skills were emphasised. A great session.

The next session was well attended. The subject was "Exploring Wine". It was well worth waiting for. A number of members from "The Amateur Winemakers & Brewers Club of Adelaide Inc" introduced the group to the art of beer and wine making.

Not only were we taught some of the manufacturing concepts and the appreciation of wines, we continually tasted the products. The wines tasted were superior to many commercial quality wines.

Everyone caught up at the evening meal and whilst eating were entertained by Simon Skinner, a magician from Aces Magic Entertainment. He proved to be very entertaining with his tricks performed at people's tables. You could tell he was good by

the stunned and delighted faces of the various people.

Sunday morning commenced with a talk from Professor Ian Maddocks AM. Professor Ian is an Emeritus professor at Flinders University who is a specialist in palliative care and is recognised internationally for tropical and preventative medicine. Professor Ian Maddocks is also the Senior Australian of the Year 2013.

Professor Ian spoke on the subject "The Healthy Spirit". He related his experiences in Papua New Guinea where he was enthralled by the co-operation between members of the village where he stayed for 14 years. Not only was there co-operation but friendship, camaraderie and thought of the other person. This he regarded as a healthy spirit. Unfortunately as time has moved on and Western influences felt, this "Spirit" has changed. Professor Ian commended everyone for being part of Polio Australia especially the retreat as it showed the spirit of helping and supporting each other.

Once again the next session supplemented the first. Bishop Bruce Rosier (Ret) introduced "The Gift of the Holy Spirit, The Comforter - Strengthening us in our Daily Life". The group was made up of people from many faiths but all showing an interest in their fellow man, all being guided by "The Spirit". Bishop Bruce explained his definition of The Holy Spirit and why. He quoted some of the Bible passages in particular from John's Gospel, quoting Jesus saying "Do not let your hearts be troubled. Trust in God, and trust in me." A wonderful way to finish the sessions.

Our final lunch was where everyone could discuss the events of the last few days, to swap addresses and to say goodbye, but not quite yet - Mary-ann and her new choir were there to enthrall us with their virtuosity and talent. What a great show.

The only way to finalise these notes is to say thank you to Polio Australia in particular Mary-ann, Gillian and John together with all of the volunteers, but a special thank you to everyone who attended and made the retreat the success that it was. 🌟

Polio Health and Wellness Retreat (Cont'd)



Thoughts on the Retreat by Ann Buchan

When I was asked last year by a physio student (commissioned by Mary-ann Liethof), to consider being involved in the Retreat in 2013, I didn't really realise what I was in for.

I first became interested in the work as a teenager, meeting as a girl guide and in the school hall at Yooralla Crippled Children's Centre in Balwyn, Victoria. The room was full of standing frames and braces and callipers. My sister had a friend who was also a Girl Guide (Julie), who had been partly disabled by polio. Then I had a physio visit the house to treat my sister for asthma, so I then knew I wanted to be a

physio (and that same physio, Pat Cosh, ended up being the head of the physio school).

I have been working as a neuro physio now for 45 years. In my private practice work, I have seen people with the late effects of polio for 30 years and am still learning.

I have been to a few polio conferences and was on a panel helping to edit the two late effects of polio handbooks with Charlotte Leboeuf (1991).

Contact with Mary-ann by e-mail certainly inspired me to see this Retreat as something rather special.

I have never given a formal plenary talk before, so the job was quite daunting - there are now so many references available and increasingly more evidence and guidelines for effective care. So where was I to start?

And so to **Thursday evening:**

The opening sharing of hopes for the three days ahead were very special, such as . . .

- We thought we had it licked.
- Learning to be better for the carer, in spite of pain and lethargy.
- Hearing other peoples' stories - and goodness, did that become quite confronting!! But exciting too when one person shared that he felt 100% better after the last Retreat!
- Issues of surgery being offered without really considering the whole of the body!
- Some had had no contact with others with PPS.
- Others could have run the whole weekend on their own experience and knowledge of the bigger picture!
- One had "blanked it all out till now"!
- Some saw it as a new chance, some looking for practical tips.
- One had been in an iron lung for 2 years, yet did national service and worked for 30+ years!
- One had been a tap dancer.
- Carers wanted to learn more.

What a great starting point for the weekend

and not a bad setting either!!

The plenary talk was hard to keep short yet relevant, not too complex and yet not oversimplifying or minimising the complex range of features in Post-Polio Syndrome (PPS) and the difficulty in diagnosis.

The 'Falls' session could have gone on for two hours - I certainly appreciated people's honesty in telling their falls story. How do you keep a balance between keeping active and not being too fearful of falling, using a crutch or stick and a splint (to effectively 'come out' and admit that there are some problems!).

Having a student, Ben, with me to demonstrate what normal balance is in the 23 year old versus a 60+ year old was helpful. And I hope that getting up off the floor will now be easier for the frequent fallers amongst the participants.

Having the opportunity to see people and a carer in the consult room was a rare treat. Too often a local pain concern is only treated locally - a painful neck may be from over activity and muscle imbalance. For some people, no one has really looked at this or the windup phenomenon of pain. Panic and fear of what it may be like

Polio Health and Wellness Retreat (Cont'd)

linked to those early traumas.

Splints need regular checking or secondary nerve compression can cause more disability. It was great to have the other University of SA physiotherapy graduates, Alex Daniel and Vivienne Maxwell, present as volunteers. Let's hope that the next generation of allied health practitioners does really **get it**.

I have some research questions:

- Were there more miscarriages amongst women who had polio?
- Is there a greater risk of bowel cancer for people in a wheelchair?
- What is the incidence of Parkinson's features later in life in people who had polio?

My thanks go to participants Lorraine, Esther, John and Fay, Pauline, Douglas, and Kate and others for raising further questions and challenging a traditional therapeutic model.

I have provided various [handouts](#) including Richard Bruno's "10 Commandments", The Challenges of Post-Polio Syndrome presentation, and a list of points as a background to the Falls session.

In my sorting of polio and post-polio notes, I came across notes given out (when I was a student) on the callipers, splints and support systems available. I was sorry not to hear Adam Holden's session on "To Brace or Not To Brace". There is certainly a greater variety of

designs and supports now. But we still need to be careful as too many modern ones end up in the back cupboard. One person I saw was getting a neuropathy from the callipers being too tight.

It was a treat to be able to attend.

Suggested additional reading:

[Explain Pain](#) by Dr David S. Butler and Prof G. Lorimer Moseley (Noi Publications, Adelaide Australia, 2003)

[Clinical Neurodynamics](#) by Michael Shacklock, published by Elsevier, 2005.

[The Late Effects of Polio](#): Introduction to Clinical Practice by Polio Australia, 2012

[The 10 Commandments of PPS](#): (Richard Bruno and Nancy Frick) 🟡



Room with a View



Ann and Ben (left) presenting 'Falls' Session

Touched by Polio: from casts to catharsis

Since this exhibition was launched in March earlier this year, 19 of the 35 artworks have been sold for between \$150 and \$500 each, raising a healthy total of \$4,455.

As Polio Australia receives no government or any other regular funding, the *"Touched by Polio"* exhibition artworks have been generously donated by the artists for auction/sale, with all proceeds going to assist Polio Australia in continuing their work to provide services for polio survivors.

The remaining 16 pieces are currently on show at:

Coonara Community House
22 Willow Road
Upper Ferntree Gully
Victoria Australia

Coonara is open between 9.00am and 4.00pm Monday to Friday and the exhibition can be seen until Friday 19th July.

As we are keen to promote this exhibition widely, if you have a solid contact for **free** exhibition space in the Melbourne metropolitan area, please contact [Mary-ann](mailto:Mary-ann@polio.org.au).

All these artworks are still for sale and can be viewed online here: www.polio.org.au

1. *Boot Full of Blooms* by Margaret Greig
2. *Bound* by Kat Panourgias
3. *Butterfly* by Dianne Kennedy
4. *Dancing Queen* by Frances Henke
5. *Evening Wear* by Wendy Davies
6. *My Elusive Dream* by Nola Stewart
7. *Out for a Fling* by Margaret Greig
8. *Reaching* by Judith Maxwell
9. *Said Leg* by Maureyn Brees
10. *Splish, Splosh, Splash* by Heather O'Flaherty
11. *Steep Ascent* by John Marsh
12. *Story Time* by Frances Henke
13. *Surveying His Farm* by Margaret Greig
14. *The Long Climb* by Pauline Derrick
15. *The Party Frock* by Marilyn Dixon
16. *Walking Tall* by John Marsh

If you simply must have one of these amazing pieces, email [Mary-ann](mailto:Mary-ann@polio.org.au) with your offer. And remember, it's all for a good cause!

Note: Postage costs will vary according to size and destination, and will be added to the purchase price.

- Ed



Touched by Polio

"You could say that Polio is an equal opportunity virus. It doesn't discriminate between generation or gender . . ."

~ Roslyn Dux ~

(artist touched by polio in 1955, aged 7)

"My mum was exposed to polio as a baby and was diagnosed with Infantile Paralysis by the time she was 18 months old. It affected her right leg.

For many years, it never really occurred to me that Mum even had a disability, for such was her optimism and strong character that her physical restrictions didn't even register."

~ Heather O'Flaherty ~
(artist)



"Like most polio people, my childhood was a manic mixture of operations, callipers, night splints and physical restrictions."

~ Nola Stewart ~

(artist touched by polio in 1945, aged 6 months)

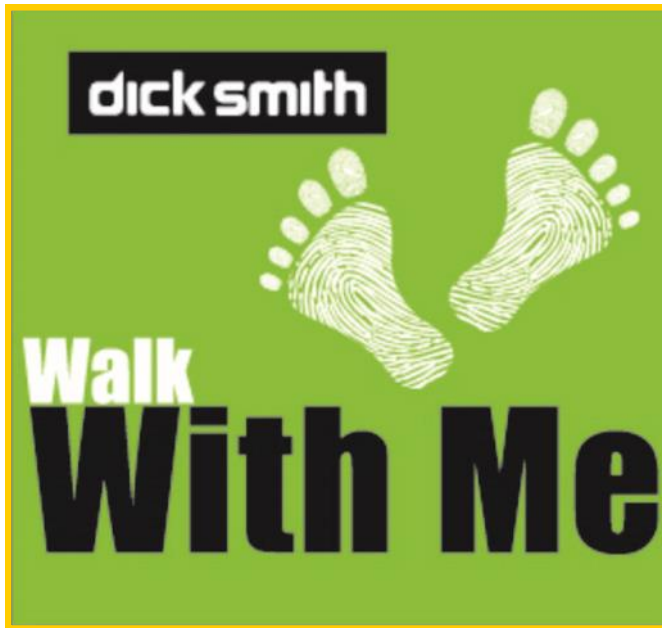


POLIO AUSTRALIA
Representing polio survivors throughout Australia



Clockwise from top left:
Butterfly, The Party Frock, Splish, Splosh, Splash,
and My Elusive Dream

Walk With Me 2013



Polio Australia is, once again, delighted to be partnering with Scope for the [Walk With Me Melbourne](#) on Sunday 1st September 2013 (*Fathers Day*), and with Northcott for the [Walk With Me Sydney](#) on Friday 13th September 2013.

Last year, we only had 2 'walkers' - John Tierney and Fran Henke - who still managed to raise \$3,770 between them! (*pictured below*)

The difference we can make together

Funds raised for Walk With Me will be used by Polio Australia to pay for much needed program development including annual Polio Health and Wellness Retreats, regular polio-related publications, Clinical Practice Modules, community education, and systemic advocacy.

Walk With Me 2013

Walk With Me is a national walk that celebrates the achievements of people with a disability. The event will foster awareness and inclusion while raising much needed funds for organisations that support people with a disability across Australia.

Walk With Me is not a fun run, nor a competitive fitness event but a recreational walk. It provides family, friends, colleagues, businesses and members of the general public with the opportunity to make a difference in the lives of people with a disability.

So take the challenge, choose an event in your area and Walk With Me!

How to get involved

- **Join our walk** – register to get involved with this inclusive community activity
- **Sponsor a walker!** - choose who you would like to support – donations are tax deductible and can be made online.

Simply go to [Polio Australia's Walk With Me](#) web page and follow the prompts. And keep checking the webpage for updates leading up to the events.

Melbourne

When: Sunday 1st September
Where: Birrarung Marr, Melbourne
On the Day Registration: 9.00am
Pre-registration check in: from 10.00am
Pre Walk Warm Up: 10.45am
Walk Starts: 11.00am
Entertainment: 11.30am – 1.00pm
Event Concludes: 1pm
Tickets: \$50 family, \$25 adult, \$10 concession

Sydney

When: Friday 13th September
Where: Banks of Parramatta River (between Barry Wilde Bridge and Rivercat Wharf Parramatta)
On the Day Registration: 11.30am
Walk Starts: 12.30pm
Entertainment: 11.30am – 2.00pm
Tickets: Free

For further details, email:
office@polioaustralia.org.au

- Ed

Dr John Tierney at the 2012 Walk With Me event in Melbourne



Fran Henke at the 2012 Walk With Me event - completed in Hastings

Feature: Polio Network Members of Polio Australia

Polio Australia is the peak, national body representing polio survivors in Australia. The Committee of Management is made up of two representatives from each of the original six state polio networks.

In this edition of *Polio Oz News*, we are featuring Polio Network Victoria (PNV), a service of Independence Australia. The following article was provided by PNV's Information Services Community Worker, Jen Sykes.

The story of Polio Network Victoria begins with Edith Hall AM. From 1982-89, Edith was the Executive Officer of Independence Australia (formerly Paraplegic and Quadriplegic Association of Victoria, founded in 1957). She had polio in 1937 and was acutely aware that nothing was being done in Australia for polio survivors.

In 1987 she attended the fourth Polio Survivors Conference in St Louis, Missouri, USA, and brought back books, leaflets, papers, audio and videotapes. The Board of ParaQuad was sympathetic to establishing a polio network, so she held a public meeting to which 125 people turned up.

Beth Brodribb, who had been working with ParaQuad's sheltered workshop, was asked to help with the network. Her job was to gather and disperse information. Copies of material Edith brought back were sent interstate and within a year networks of polio survivors were formed in each state and territory.

In 1989 the network changed its name to the Australian Polio Network and began a social program for members, numbering well over 500. Beth Brodribb attended some international conferences and like Edith before her, returned with valuable resources. One of the issues the network had to tackle was educating health professionals about the late effects of polio. In 1989 the Department of Community Services approved a small amount of funding for 12 months, which was used to produce and distribute the network's newsletter. The need to target health professionals led to a symposium held in April 1991 in conjunction with Datech Expo '91. Health professionals came to learn from the group, generating more enquiries. A post polio clinic was set up at Bethesda Hospital in mid 1991, run by Dr Peter Colville.

In 1995 the network changed its name to the Australian Polio Network (Vic) then to Polio Network Victoria (PNV). In 1994 there were two community officers based at ParaQuad whose roles were to help set up groups in areas where they did not exist, promote polio immunisation, raise

awareness of needs, organise workshops and provide guest speakers to community groups and schools.

In 1996 the first Polio Day was held in Ballarat attracting more than 100 people. The focus of the day was social and for many people it was an opportunity to meet up with other polio survivors they had not seen for decades. It was such a success it was decided to run one annually.

As of 2012 there were 15 polio support groups across Victorian metropolitan and country areas. The Information Services Community Worker is in regular contact with the Polio Support Group convenors and visits the groups where able. The Polio Advisory Committee (PAC) was formed in 1991 from members of PNV and achieved a great many things including information booklets, PNV's website, and "Post-Polio Syndrome: The Australian Experience" DVD to name a few.

In 2011, following a review of the support services at Independence Australia, the PAC was disbanded and replaced by the Polio Reference Group (PRG), with membership more in line with representation of the support groups. This group oversaw the organisation of PNV's 25 year celebrations in 2012 at Melbourne Zoo.

PNV has 2 representatives on the Polio Australia Committee of Management; Jen Sykes, Information Services Community Worker at Independence Australia, and Gordon McKinnon from the Warrnambool Post-Polio Support group, and member of the PRG.



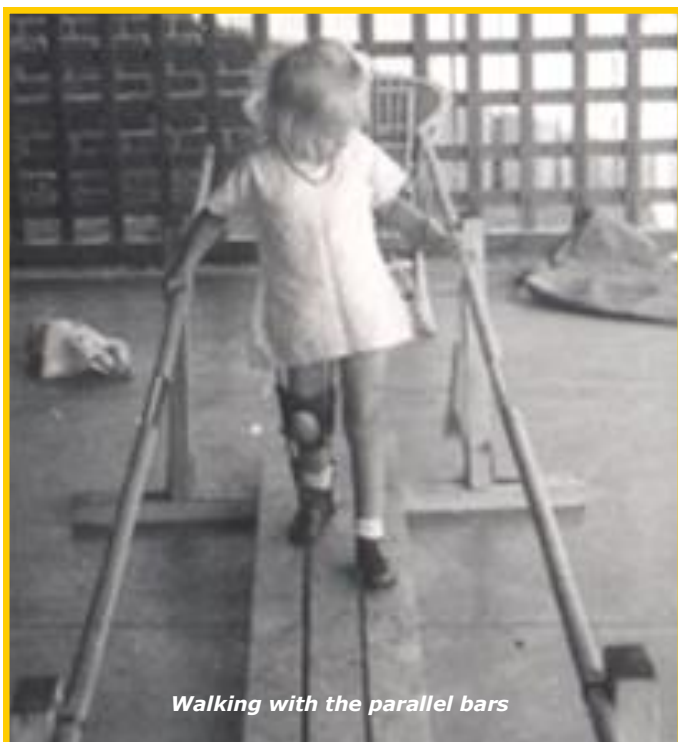
Jen Sykes



Gordon McKinnon

Note: Gordon replaces long-term Management Committee Member, Michael Judson, who sadly passed away due to cancer in April 2013. - Ed

My Story by Elizabeth Edmondson



Walking with the parallel bars

Although I was born on July 1st, over 60 years ago, my story really began on September 27, 1951, when at the age of 15 months; I was taken to hospital and diagnosed with polio. I spent the next fifteen months in the Golden Age Hospital.

Towards the end of my stay in hospital, I was allowed home for the weekends. I would go home with both legs in plaster, with a wooden bar holding my legs together.

When I was at home, later on, every night I had to sleep with my legs in plaster and my back tied down onto the bed. I became very good at winding bandages each morning. One night, I lifted up my legs vertically, and then back down onto the bed. As a result, all my blankets were under my legs, and as it was in winter I never did this again, as I was cold for the rest of the night.

When I came home at 2½ years, my father made me parallel bars so I could learn to walk. I was given a jelly bean for every length I walked. Later on I would go to the Golden Age Hospital, for physiotherapy lessons. There was a large warm bath, probably 3 meters square, where several children would sit in the bath doing exercises. I was 6 when my sister Pam was born. One time, when going to my lessons, my mother hadn't locked the pusher properly,

and the pusher collapsed with Pam inside. Mum quickly opened the pusher and up popped Pam like a Jack in The Box! I thought it was funny but Pam was not amused. Mum also helped me do exercises on the kitchen table - we used to listen to Jason and the Argonauts on the ABC radio.

I started swimming when I was about 5, learning to swim at the Crawley Baths in the Swan River. My coach would walk along backwards, with his hand under my head, while I swam backstroke. For dog paddle and freestyle, he had a piece of wood on a rope, which I would hold onto. While he towed me up and down the pool, I would be swimming freestyle or dog paddle. You had to be quick, so that you didn't let go of the wood completely. My first success in swimming was coming 3rd in the dog paddle race in year 1 at the school sports. I never used my legs for swimming.

In those days, my calliper did not bend at the knee. At about the age of ten, I finally had a calliper that would bend. I was so happy going to school on the bus, wanting to show off this wonderful new calliper that bent at the knee. My friends weren't impressed as their knees bent all the time! Also, I used to have to get special boots made for me, to support my ankles. As my feet were growing rapidly, the Orthotics department would cut the toes out of my shoes so I would have more room to grow.

In early 1964, when Pam was nearly 8, Mum took her to Tony Howson to learn to swim. I said I would like to go too, as it was one sport I could do. He lived in a Commonwealth Games House in City Beach which had a 25 yard pool in the back yard. Very soon, Tony suggested I joined his Swimming Squad at Beatty Park, which I did.

One day Tony came up to me and said "*You have just broken a world record*". Before I knew it, at the age of 14, I was competing in the Adelaide selection trials for the Paralympics to be held in Tokyo. At the age of 14 years and 4 months, (the youngest person to represent Australia) I went to Tokyo, and won 3 gold medals and broke three world records in the 55m freestyle, breaststroke and backstroke. I was not selected to go to the Commonwealth Games in 1966, but went to Israel in 1968, and won 2 gold medals (also world records) and 1

My Story by Elizabeth Edmondson (Cont'd)

silver in the 50 meters backstroke.

I stopped swimming after this, as I had to earn my living. Whilst working at Telstra I met and married Ken. We had one daughter Ruth, but unfortunately we separated when she was 3. Ruth is now 24 and studying at the Australian National University for her doctorate.

In 2000, I was awarded the Australian Sports Medal in recognition for my services to swimming. I returned to competitive swimming in September 2006, and as a result my health has improved greatly. I am an active member of the Stadium Snappers Masters Swimming Club. In April 2008, I swam in the 800m freestyle event in the World Masters Games held in Perth and in June I was an inaugural inductee into the WA Swimming Hall of Fame.

In December 2008, I was diagnosed with breast cancer and underwent a lumpectomy. After surgery, I wrote to my friends and told them I now had one concave and one convex breast. One friend then asked "Does that mean you will swim round in circles?" Luckily, when I resumed swimming in early 2009 I was still able to swim in a straight line!

I competed in the Australian Masters Games in Geelong and Masters Swimming in May 2009. I then had 6 weeks radiotherapy in May and June, resuming training in July for the World Masters Games held in Sydney in October where I won 4 gold and 1 silver medal.

In 2009 I was lucky to win 22 gold, 4 silver and 1 bronze medal which doubled my medal collection in one year. I was also inducted into the Wheelchair Sports Hall of Fame.

In 2010, I went to Launceston to compete in the Masters Short Course Games. I was very pleased

with my results as I broke 11 PB's out of a total of 12 events. I was also lucky to win a bronze medal in the 4 x 25 Medley Relay. I then swam in the State Short Course Championships in Perth and broke another 6 PB's out of 7 races. I celebrated turning 60 in 2010 by breaking 60 PB's! (oops I ended up breaking another 3!)

In 2011, I had a new challenge to face - I was diagnosed with post-polio syndrome in my right arm, but still competed in the 2011 Australian Masters Games held in Adelaide in October. I won 6 individual gold medals and 4 relay medals.

In 2012, I had surgery on my left shoulder in February, but am now back in the pool and swimming slowly.

I intend to keep swimming for as long as I can, as the motto for the World Masters Games is "Fit, Fun and Forever Young" a wonderful quote to live by. 🌟



Home from World Masters Games 2009



Me with big sister Jo



Arriving home from Tokyo November 1964



Showing my medals to family and friend on my return from Israel 1968

My Treatment in Hobart

by Carol Squires

I contracted polio in 1949, aged four, and spent the next three years in hospital. I left hospital with one leg shorter and one foot smaller and other associated problems.

No major issues were experienced until ten to twelve years ago when I developed muscle weakness, tiring quickly and burning sensation in my legs.

Four years ago I went to see Dr Stephen de Graff in Melbourne, a Rehabilitation Specialist who treats people with the late effects of polio. Steve suggested I consult a Neurological Physiotherapist, so on returning home, my GP referred me to Phil Ladlow at [Allcare Physio in Sandy Bay](#). Phil has a Masters in Neurological Physiotherapy, and is a qualified instructor of Rehabilitation Pilates. Phil is also a Clinical Advisor to Polio Australia.

After initial consultations, Phil recommended I try Rehabilitation Pilates in a group of three people conducted by him, so it was almost like having one-on-one sessions, with exercises tailored to my condition.

Over a period of four years, I have made good progress doing stretching, core strength, posture and muscle improvement exercises using various pieces of Pilates equipment and a routine of exercises at home. I have since progressed to another Pilates group of five conducted by Jasmin Rattray but with all exercises set by Phil.

For anyone having polio related problems in Hobart, I would certainly recommend seeing Phil at Allcare Physio in Sandy Bay. He has helped me so much, and I am now going forward not backwards. ●



Physical Disability Australia



Physical Disability Australia (PDA) exists to proactively embrace and promote difference and diversity for an inclusive society'.

Want to become a member of PDA? Contact PDA by phone on 02 6567 1500 (9am - 5pm Monday to Friday), email at <mailto:pda@pda.org.au>, or go to: www.pda.org.au, complete the form and return to PDA. It's free if you have a disability and \$27.50 for organisations.

Anyone interested in receiving PDA's regular bulletins should send an email with 'subscribe' in the subject heading to communications@pda.org.au and include in the email that they wish to subscribe and they will be added to future bulletins. ●

Access All Areas

Source: [Senator Rachel Siewert Website](#)

Access All Areas

The Access All Areas map below is a compilation of universal access issues throughout Australia submitted by people with disability, their carers, family and friends, using the Access All Areas app for iPhone.

When the reports start coming in you will be able to zoom in and move the map to see the feedback submitted from your area.

To add your own feedback, get the *Access All Areas* iPhone, iPad or Android application and send us a report.

Get the [app for Apple iOS here](#).

Get the [app for Android here](#).

If you don't have one of the devices then simply email your feedback with the location and a photo to senator.siewert@aph.gov.au.

Most of us take for granted that we can easily go to the bank, shops, pool, have coffee with friends, attend concerts and sporting events, and all the other many different things we do in our ordinary everyday lives. However, for people with disability such simple everyday tasks can be extremely challenging. The lack of accessibility for people with disability in our communities limits people's independence and compromises their quality of life. More than 27 per cent of respondents to a recent disability survey identified lack of access to the environment as a barrier to their full participation in the life of the community.

The Australian Greens want to make sure our communities are accessible for everyone.

We recognise that this will require the efforts of local, state and federal governments, as well as businesses, groups and individuals. Together we can work to increase understanding and awareness of this issue and to create more inclusive communities to the benefit of us all.

People with disability, their carers, friends and families, are invited to share your experiences of participating in community life and help us to keep access on the agenda.

So tell us, where are the most obvious barriers to the participation of people with disability in your area? We know that the community is diverse and that everyone has different needs. What are

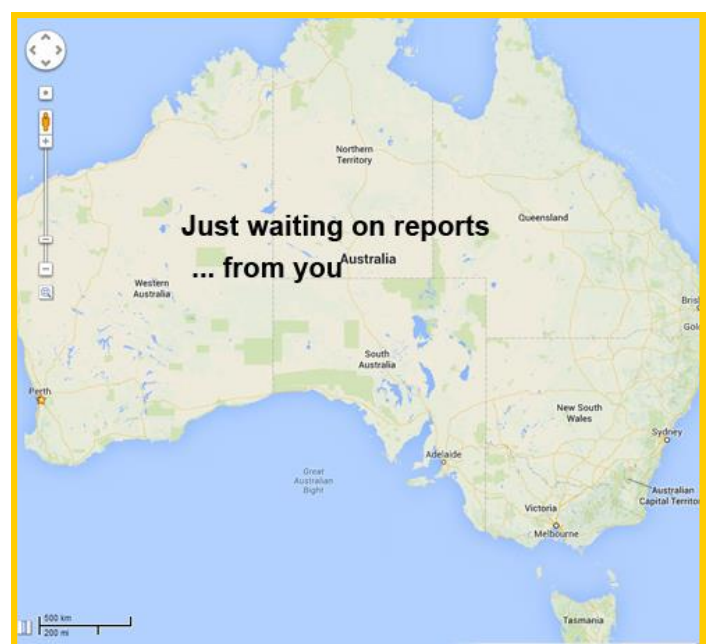
the specific challenges you face participating in your community? Is it steps, footpaths, toilets, audio loops or parking? What change is needed for you to be able to access all areas? (Photos really help, so make sure you include one so we can see what you mean).

But the app isn't just about the barriers. We also want you to tell us the positive experiences. We want to be able to share the good news when services, businesses, events and facilities are inclusive and easily accessible to all people.

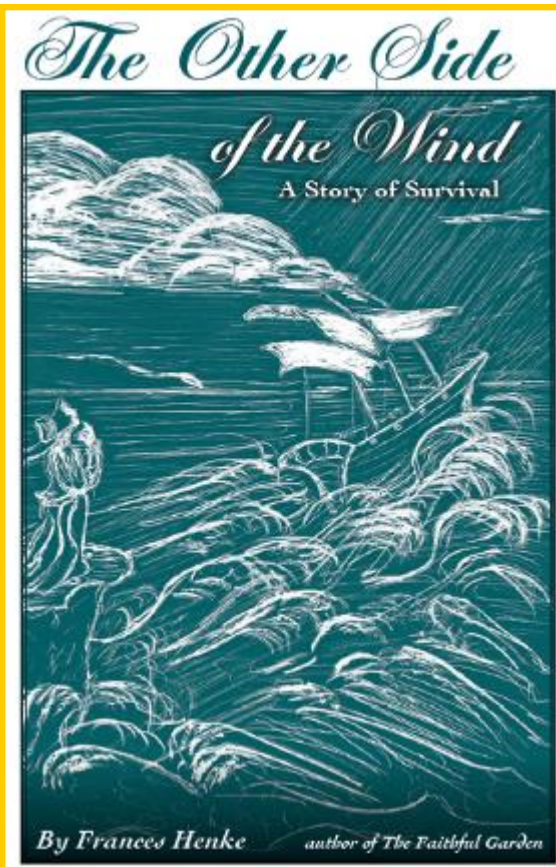
Your feedback is sent to the Greens Spokesperson for Disability Issues, Senator Rachel Siewert. The Greens will collate the information from the app and prepare a report which we will present in Parliament. Personal contact details will not be made public or included in any reporting.

We will also make the formal report publically available so this information can be fed into other government processes including the work of the Australian Human Rights Commission and local government.

Let's work together to make our communities more inclusive. [You can read more about our plans for the Access All Areas app here](#). 🌐



Fran Sails Into Publishing For Her 70th



Some people jump from a plane or go up in a balloon to mark their 70th birthday, but Fran Henke has published her first novel, a true story of love and survival in the extraordinary days of early Victoria.

"The Other Side of the Wind: A Story of Survival" was launched on June 22 by Dr Mary Ann Ghaffurian, daughter of Lucy Purcell who more than 20 years ago told Fran a story of the arrival of her ancestors to Geelong.

Author of 13 non-fiction books, Fran, a polio survivor, always wanted to write fiction but journalism intervened. A career in print, radio and publishing saw her working in London, Sydney, Melbourne and regional newspapers. She spent almost four years as a member of the Commonwealth Film Censorship Board and has written books on gardening, leading to columns on gardens for magazines and newspapers.

As well as working as a media advisor for State and Federal MPs, Fran's work in raising awareness of the needs of polio survivors has seen her win community service awards. She is chair of the Polio Reference Group, Victoria.

But the story she heard in 1992 caught her imagination. Extensive research brought the story to life and led her to write **"The Other Side of the Wind"**.

"Mrs Purcell told me that her ancestors came out to Australia on a sailing ship, landing at Pt Henry, near Geelong," Fran said.

"There was no wharf in those days so boxes and bags were thrown onto the beach. The couple found one was missing, so the husband when back to the ship to find it, but the wind changed and the ship – with him on board – took off through the Heads, leaving his wife stranded on the beach. It took him six months to get back to Australia".

So, **"The Other Side of the Wind"** is set in 1851 in the new colony of Victoria. Boom town Geelong has grown on the sheep's back, to become the main destination for people arriving to join the gold rush.

These people are making new lives – conservative graziers, bureaucrats with brutal pasts in the penal settlements, extroverted individuals determined to make their fortunes, ordinary folk escaping the clearances.

Women are playing a key role, throwing off the shackles of old world convention, blazing trails in unexpected directions. They are striving to survive, to bring kindness and quality to the

male-dominated society with its military rule under pressure from free settlers and free thinkers.

This is the robust canvas onto which the newly married couple, Edward and Catherine Anderson, arrive. They become unexpectedly separated after a wind shift sees Edward left on board and Catherine stranded in the new colony.

How will the fragile artist Edward cope again at sea? How will Catherine manage in the frontier town without money and her beloved husband?

"The Other Side of the Wind – a story of survival" by Frances Henke was launched on June 22 in Mornington by Dr Mary Ann Ghaffurian, daughter of Lucy Purcell, who related the story more than 20 years ago; and on June 20 in Fran's 'home country' of Gippsland by Mirboo North bookseller Susan Lendon, satisfying the author's Geminian inclinations for two of everything.

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Paralysed with Fear: the Story of Polio

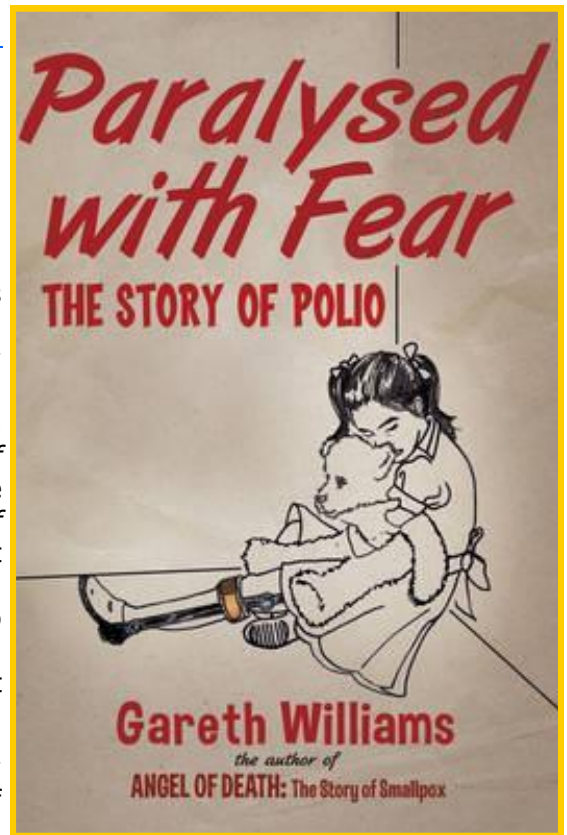
Source: [The Lancet, Volume 381, Issue 9880, Pages 1805 - 1806, 25 May 2013](#)

Paralysed with Fear: the Story of Polio by Gareth Williams

Palgrave Macmillan, 2013336
ISBN-9781137299758

Contrary to the signature opening of the television series *Star Trek*, Gareth Williams, professor of medicine at Bristol University in the UK, has decided to boldly go where many men and women have gone before. Like Richard Carter in *Breakthrough*, or Tony Gould in *A Summer Plague*, or Aaron Klein in *Trial by Fury*, or John Paul in *A History of Poliomyelitis*, or Naomi Rogers in *Dirt and Disease*, or Jane Smith in *Patenting the Sun*, or John Wilson in *Margin of Safety*, or Nina Seavey in *A Paralyzing Fear*, or, most notably, David Oshinsky in his Pulitzer-Prize-winning, *Polio: An American Story*, Williams has written a book about polio and the polio vaccine. Remarkably, in *Paralysed with Fear: the Story of Polio*, Williams has made a significant contribution.

Williams doesn't shy away from the science. He begins by detailing the discovery of poliovirus and its method of spread in a manner so dramatic that we can't wait to turn the page, even though we already know the ending. He accomplishes this feat by mixing a conversational tone ("*This is a good moment to put the science of polio to one side*") with great writing ("*If smallpox was a mass murderer, then polio was a sniper, and all the more menacing because nobody would see where the fatal shots had come from*"). In describing two experimental polio vaccines from the 1930s that had inadvertently paralysed and killed several children, Williams writes, "*like the head of traitors stuck up around the walls of a medieval city, they were also a warning to others not to go down the same dangerous path*". Williams also affords the virus human qualities; when describing a successful vaccine, he writes, "*[Polio] had unwisely chosen to target the American people, and therefore set itself up for revenge through the might of American science.*" 🟡



New Handicapped Sign Rolls Into New York City



Source: [North Country Public Radio \(USA\)](#)

The handicapped [sic] sign is getting a new look — at least in New York City.

The initial design, created in 1968, depicted a person with no head in a wheelchair. The sign has changed since then — the figure eventually got a head — and now it's trying something new.

Sara Hendren, a Harvard graduate design student, is co-creator of a guerrilla street art project that replaces the old sign with something more active.

"You'll notice in the old international symbol of access, the posture of the figure is unnaturally erect in the chair," she says. "There's something very mechanical about that."

Hendren's new design looks more like a person wheeling him or herself independently. "Ours is also leaning forward in the chair. There's a clear sense of movement, self-navigation through the world," she says. Read more [here](#). 🟡

Fatal Fears Over 'Modern Polio'

by **Hugh Whitfeld**

Source: [7News](#) - 19 June 2013

A special panel of doctors has been set up to investigate an outbreak in Sydney of a new super virus, linked to the deaths of four children.

One hundred more have been infected by the highly contagious virus which is being called "modern polio".

The Sword family has photos and memories, but they cannot hold their baby Bethany (*pictured right*), who died aged 19 months from EV71.

"In the space of two days, she'd gone from a relatively healthy kid to gone," father Luke Sword said.

Enterovirus 71 has killed hundreds in Asia. It was first noticed among toddlers on the Northern Beaches.

"That night [my daughter's] heart rate monitor went off five times before I even realised that something wasn't right," Sydney mother Saartje Destoop-Timmony said.

Zali spent a week in hospital after picking up the virus spread through bodily fluids like saliva at childcare. The virus is a strain of the common hand, foot and mouth disease and similar to polio which is deadly, but now eradicated.

Doctors say if you notice symptoms like high fever, drowsiness, a blister-like rash, jerky movements, unsteadiness on feet, and heart and lung inflammation then you should seek help.

"I understand they don't want to scare the population, but on the other hand I felt like I wasn't educated about it," mother Saartje Destoop-Timmony said.



When a child arrives in hospital there is no magic bullet drug or treatment, they are simply prescribed fluids and bed rest.

It is a virus worrying doctors because they know little about it, including why it is killing some kids, and not others.

A special medical panel has been set up.

"We're very much working with the hospitals to learn as much as we can about the disease in Australia," Dr Vicki Shepherd said.

The New South Wales Health Minister says the department always takes *"these outbreaks very seriously."*

"I'm advised by the experts but this is not something that should panic people." Jillian Skinner said.

Parents are being urged to make sure their children wash their hands thoroughly, especially after using the bathroom, and before eating. And to use a tissue when sneezing.

Children under five are most at risk especially those under two. If you notice any of the symptoms listed above, you should seek help. 🌐

Bowelscan is a Rotary program developed in 1982 in New South Wales and now conducted by over 250 Rotary Clubs across Australia. These Clubs issue approximately 150,000 kits during their annual Colorectal Screening programs. Since Bowelscan commenced, it is estimated that more than 1,000 people with bowel cancer and 5,000 with polyps have been detected.

Bowelscan is a public awareness program seeking to increase community knowledge of bowel cancer and its symptoms as well as the distribution of faecal occult blood testing kits to facilitate early diagnosis.

The aims of the Bowelscan program are to:

- enhance public awareness of the need for bowel cancer screening;
- promote and coordinate the Bowelscan program annually;
- emphasise the importance of bowel cancer screening for both men and women over the age of 40.

Bowelscan is a not-for-profit initiative. The successful operation of Bowelscan, and its accessibility to a wide range of people, is made possible by the voluntary support of a large number of pharmacies, pathology laboratories and Rotary members.

Check the **[National Bowelscan](#)** website for further information.

Common Playground Illness Has Its Lethal Side

by **Melissa Davey, Health Reporter**

Source: [Sydney Morning Herald](#) - 23 June 2013



Enterovirus survivor: Nathanael Cachia, 7, with his mother Caileen. Photo: Dallas Kilponen

Like many in childcare, Nathanael Cachia contracted hand, foot and mouth disease when he was 16 months old. The doctor told his mother Caileen that it was a mild illness and to keep him quarantined until it cleared.

By the next day, Nathanael was paralysed in his right leg.

"He was incredibly miserable, vomiting and inconsolable," Mrs Cachia said. "We went to the emergency department and they found he had brain inflammation. It took them 12 hours to figure out he had an enterovirus."

Now a healthy seven, Nathanael still receives physiotherapy for his leg, which has almost regained full strength.

Enterovirus is common in Australia and is a cause of the usually mild hand, foot and mouth disease. But Nathanael was found to have the

rarer EV71, responsible for the deaths of two NSW children since late last year and suspected in the deaths of two more. Two of the children were under the age of one. Three were from metropolitan Sydney and the other from the Hunter region.

"It made me feel sick and so sad when I heard children had died recently from this," Mrs Cachia said. "I realise we were lucky. I would urge parents to take their children out of childcare if they have hand, foot and mouth disease and to go back to the doctor if their child gets worse."

A spokeswoman for the NSW Ministry of Health said the latest data provided through NSW Health's surveillance system showed the incidence of enterovirus cases had dropped since March. *"We have sent alerts across the state, including media releases for the general public and targeted messages to general practitioners, emergency departments and childcare centres,"* she said.

There are no plans to make enterovirus a notifiable disease, whereby doctors are required to alert health departments.

"The reasons for making a disease notifiable include two main criteria - whether we can prevent further spread from an individual case by public health action, and whether we can gather data about each case to contribute to a better understanding of how to prevent it in the absence of alternative methods," the spokeswoman said.

"Hand, foot and mouth disease and enterovirus do not meet these criteria."

Bruce Thorley, of the Victorian Infectious Diseases Reference Laboratory, stressed that in most cases EV71 caused no symptoms or did not progress beyond hand, foot and mouth disease. *"These hospitalisations and deaths are very severe cases,"* he said.

His laboratory had been notified of children admitted to hospital with paralysis and neurological symptoms, who are then tested to exclude polio. Though eliminated in Australia, polio may be imported from overseas.

"In excluding polio from these cases, we found they had a specific strain of EV71, called C4a," he said. *"I don't think we need to be alarmed, but we do need to be aware this strain is present."* ●

Nigeria Records Nine New Polio Cases in One Week

by **Chukwuma Muanya (Lagos)** and **Eric Meya (Sokoto)**

Source: [The Guardian](#) – 11 July 2013

After about two weeks without recording any case of Wild Polio Virus (WPV), Nigeria Thursday reported nine new cases of the crippling virus, bringing the number of cases for 2013 to 35.

According to the latest edition of Weekly Polio Update published by the Global Polio Eradication Initiative (GPEI), this is despite a sub-national Immunisation Plus Days (IPDs) held from July 6 to 9, 2013 in northern and middle-band states.

However, Sokoto State is now on the verge of becoming one of the polio-free states in the country, Special Adviser to the Governor on Primary Healthcare, Ibrahim Jibril Sokoto, has said. While fielding questions from newsmen yesterday, Sokoto said his optimism was based on the fact that though eight cases of WPV were reported in the state last year, no single case had been reported so far this year.

Sokoto attributed the progress made in the polio eradication fight to the concerted effort of all stakeholders, including the Sultanate Council, following the special measures evolved to achieve maximum coverage.

Those measures, he noted, included the use of medical doctors in a house to house campaign, and taking polio victims around to testify to people that their condition was as a result of non-compliance, as well as encouraging Quranic teachers and influential individuals to talk to the people about the safety and efficacy of the Oral Polio Vaccine (OPV).

Meanwhile, a breakdown of the figures means that, of the 108 cases recorded globally in 2013, Nigeria ranks behind only Somalia, which recorded 41 cases earlier in the year after not reporting any case for a while, and besides Afghanistan and Pakistan, Kenya has seven cases.

According to the GPEI report, the most recent polio case was type one (WPV1), from Bauchi, and had the onset of paralysis on June 18, 2013.

The report read:

No new cases of circulating Vaccine Derived type two Polio Virus (cVDPV2) were reported in the past week. The most recent cVDPV2 case had onset of paralysis on November 24, 2012, from

Kebbi.

In the Horn of Africa, an outbreak of WPV1 is continuing, centred around Banadir, Somalia. The majority of cases associated with this outbreak developed paralysis before the start of the comprehensive emergency outbreak response activities.

In any case, WPV3 continues to be at the lowest ever recorded levels. Globally, WPV3 has not been detected anywhere since November 2012 in Yobe State, Nigeria.

He [Sokoto] noted that there has been a gradual and consistent improvement in the coverage of the OPV administration and that the last three rounds had been particularly impressive with 63 per cent of the local areas achieving over 79 per cent coverage.

The last round, he said, recorded the highest coverage of 1.59 million children out of the targeted population of 1.6 million children. On the Emergency Operation Centre (EOC), which started this year, Sokoto said that when polio finally disappears from the state, the centre, which was built by developmental partners, would focus on other childhood killer diseases. ●



Traces of Polio Continuing To Appear in Israeli Sewage

by **Hana Levi Julian**

Source: israelnationalnews.com

- 11 July 2013

Traces of the poliomyelitis virus are continuing to appear in sewage treatment facilities in southern and central Israel according to the Health Ministry.

The virus, which can cause paralysis, was once considered eradicated. But nearly one million doses of the "live attenuated" oral vaccine were ordered at a cost of several million shekels after the live virus was first detected in February in routine samples of sewage extracted from Rahat.

Israel is [one of only five countries in the world](#) that routinely tests stool samples, via 16 sewage treatment plants around the country.

Health Minister Yael German stressed there is "*no reason to panic*," saying that not even one case of clinical poliomyelitis has appeared thus far.

But the ministry is continuing to monitor and examine stool samples around the country, and traces are continuing to spread. The areas where the virus has been detected include the Lev Hasharon area, Modi'in, Ramle, the Negev Bedouin city of Rahat, Be'er Sheva, Ashdod and Tel Aviv.

According to some experts who testified before the Knesset Health Committee last month, some [10 percent of Negev residents have not been inoculated](#) against the virus.

An advanced form of the oral polio vaccine is to be administered to some 150,000 children in the south this month, following last month's visit to Israel by officials from the World Health Organization and the U.S. Centers for Disease Control.

Some rabbis in Jerusalem have begun to announce their recommendation to vaccinate all children under the age of six.

Five vaccination stations were opened in Jerusalem for the purpose of distributing polio vaccines to the hareidi-religious population, which includes families who choose not to immunize their children at all.

As a result, he warned, thousands of children in the country could be at risk. 🌐

Injectable Polio Vaccine May Be Introduced

by **Asif Choudary**

Source: Dawn.com - 4 June 2013

In a major development, the injectable/inactivated polio vaccine (IPV) is likely to be introduced for the first time in Pakistan to help overcome the crippling disease more effectively, Dawn has learnt.

The IPV is said to be highly effective in preventing paralytic disease caused by all three types of poliovirus and is currently being used by a majority of the polio-free developed and advanced countries.

The inactivated poliovirus vaccine is injected into a muscle or under the skin and is usually given by a healthcare professional in a hospital,

clinic, or provider's office.

Pakistan is one of the three polio-endemic countries which have been using oral polio vaccine (OPV) since the disease has hit the country.

The Polio Eradication and Endgame Strategic Plan 2013-18 of Global Polio Eradication Initiative (GPEI) had hinted at the new scheme in its April 2013 report of introducing IPV for the first time in three polio endemic countries -- Pakistan, Afghanistan and Nigeria.

"The polio programme in Pakistan is collaborating with the Aga Khan University, Karachi, to pilot the use of IPV with OPV in 2013 as an additional tool to rapidly build an immune response in children who have not been easily reached through regular

polio campaigns or routine immunization", the report said.

It says Pakistan will investigate the operational feasibility of using IPV with OPV in campaigns in the areas of Fata and Balochistan where difficult access and management issues have prevented the programme from building immunity to the levels needed to interrupt transmission.

These efforts will be combined with other health promotion activities and the mobilization of pediatricians to address other health concerns of families.

Relevant support activities will include training of health worker communications development, cold-chain management and development of vaccine management strategies. 🌐

Polio This Week

Source: [Polio Global Eradication Initiative](#) - as of Wednesday 9 July 2013

Wild Poliovirus (WPV) Cases

Total cases	Year-to-date 2013	Year-to-date 2012	Total in 2012
Globally	108	91	223
- in endemic countries	56	87	217
- in non-endemic countries	52	4	6

Case Breakdown by Country

Countries	Year-to-date 2013				Year-to-date 2012				Total in 2012	Date of most recent case
	WPV	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Pakistan	18			18	19	2	1	22	58	6-Jun-13
Afghanistan	3			3	11			11	37	6-Jun-13
Nigeria	35			35	41	13		54	122	18-Jun-13
Somalia	45			45					0	08-Jun-13
Kenya	7			7					0	03-Jun-13
Chad					4			4	5	14-Jun-12
Niger									1	15-Nov-12
Total	108	0	0	108	75	15	1	91	223	
Total in endemic countries	56	0	0	56	71	15	1	87	217	
Total out-break	52	0	0	52	4	0	0	4	6	

Data in WHO as of 10 July 2012 for 2012 data and 09 July 2013 for 2013 data.

Emergency in the Horn of Africa

The race is on to put a stop to polio in the Horn of Africa. Earlier this month an emergency outbreak response meeting was convened jointly by the Regional Directors of the Eastern Mediterranean and African Regions of WHO in Cairo, Egypt, to ensure inter-country and inter-regional coordination, analyse the risk of further spread and consolidate robust cross-regional response plans.

Vaccination rounds have already been held in the vicinity of recent cases in [Somalia](#) and Kenya and plans are in place for further rounds, including in nearby Ethiopia, South Sudan and Yemen. In Somalia's Banadir Region – which includes the capital Mogadishu, where the first case was identified – [adults as well as children are being given polio vaccines](#) in an effort to stop the outbreak rapidly.

So far 45 cases have been reported in Somalia and 7 in Kenya. 🌍