



Polio Australia



Annual Report July 2012—June 2013

National Patron: Dr John Tierney PhD, OAM, Federal Senator for NSW 1991 - 2005

Suite 119C / 89 High Street Kew Victoria 3101
PO Box 500 Kew East Victoria 3102

Telephone: 03 9016 7678 / Email: office@polioaustralia.org.au
www.polioaustralia.org.au / www.polio.org.au / www.stillhere.asn.au

Polio Australia

Our Vision

All polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed lifestyle choices.



Our Mission

Polio Australia is committed to standardising quality polio information and service provision across Australia for polio survivors.



Our Values

are encompassed in the following statement:

As the national peak body, Polio Australia represents the needs of the post-polio community and works with **passion** and **professionalism** to educate, advocate and **achieve** recognition for polio survivors.

The purpose of Polio Australia is to . . .

Educate and inform polio survivors, their families and carers, and the community at large about the late effects of polio.

Provide information, education and training to General Practitioners and a range of medical specialists and other health professionals to improve the diagnosis and management of the late effects of polio.

Facilitate the provision of appropriate and consistent health, disability and aged care support services across all states and territories to improve the treatment and management of the late effects of polio.

Provide outreach to culturally and linguistically diverse and Aboriginal and Torres Strait Islander polio survivors to ensure their diverse needs are being met in a culturally appropriate way.

Advise governments on policy development and programs in relation to the late effects of polio.

Stimulate research into the late effects of polio.

Assist the state Networks to support polio survivors and their families, friends and carers at the local level.

Facilitate and encourage the co-ordination and further development of activities within and between the state Networks.

Support and promote polio immunisation at a national level, and provide assistance to the state Networks to do so at the local level.



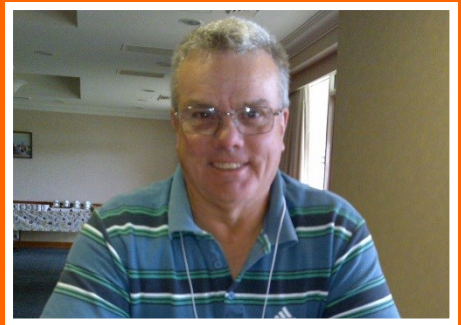
Our Committee of Management



John Tierney NSW
President



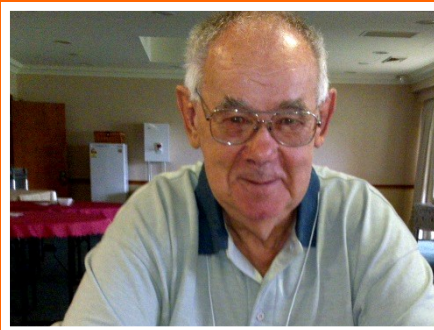
Gillian Thomas NSW
Vice President



Brett Howard SA
Treasurer



Jenny Jones WA
Secretary



Arthur Dobson TAS



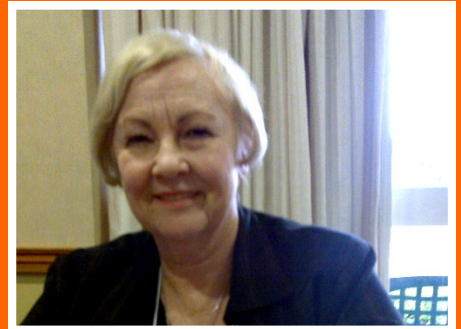
Tessa Jupp WA



John Mayo QLD



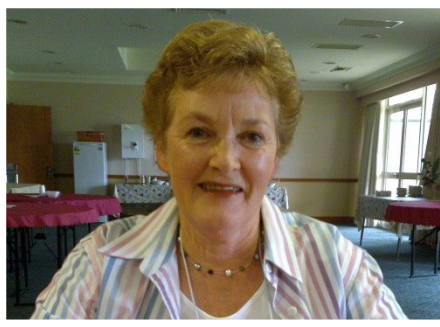
Michael Judson VIC



Margaret Peel QLD



Jen Sykes VIC



Billie Thow TAS



Peter Wierenga SA

Our Committee of Management



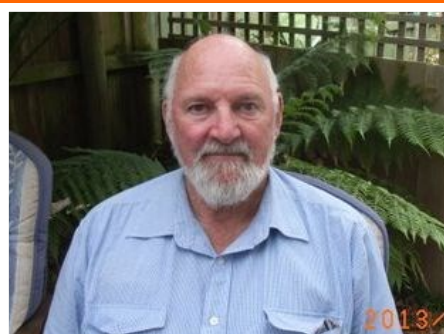
Vale Michael Judson

1948 - 2013

The Committee of Management was very sad to hear of Michael Judson's diagnosis of terminal cancer in January 2013. Michael was one of the inaugural committee members of Polio Australia, representing Victoria. His key strengths lay in the areas of financial and constitutional matters and his contribution to the overall governance of Polio Australia was valued.

Michael died in April 2013. His presence will be sorely missed.

Special thanks to Gordon McKinnon who stood in for Michael Judson from January 2013.



Gordon McKinnon VIC

Post-Polio Victoria
Granted Observer Status

At the 2012 AGM, Polio Australia formally welcomed a Post-Polio Victoria (PPV) representative, members having previously agreed to provide PPV 'observer status' at future Committee of Management meetings.

PPV's role is to advocate on issues related to post-polio to health professionals, services and government authorities.

Our strategic priorities

Polio Australia was incorporated in 2008 and is governed by a Committee of Management made up of two representatives from each state Polio Network:

- Polio NSW Inc (previously Post-Polio Network (NSW) Inc)
- Spinal Injuries Association Inc (QLD)
- Polio SA Inc (previously Post Polio Support Group of SA Inc)
- Post Polio Network - Tasmania Inc
- Polio Network Victoria (a service of Independence Australia)
- Post Polio Network of WA Inc

At its 2011 Annual General Meeting and Strategic Planning Meeting, Polio Australia's Committee of Management decided on four priorities to work towards over the next three years.

Priority One

Capacity Building: Securing a stable income stream to support Polio Australia and our key program areas into the future

Priority Two

Education: Promoting enhanced knowledge and management of the Late Effects of Polio across the Health and Community sectors

Priority Three

Health Service Promotion: Lobbying and advocating for recognition of and appropriate service provision for Australia's polio survivors

Priority Four

Collaboration: Working with and supporting state-based Polio Networks by producing resources and standardising polio information for use by the Networks and their members



The year at a glance

We are constantly applying for 'project funding' to try to finance these activities - most of which are ultimately achieved through goodwill . . .

July 2012	Fundraising Consultant, Glenn Gardner, engaged to work on developing a 'Patrons Circle' and to work on strategies to get Rotary Clubs more connected and willing to donate to the work being done by Polio Australia.
August	Mary-ann spoke to first year students at La Trobe University's National Centre for Prosthetics and Orthotics regarding the needs of polio survivors. This provided an opportunity to recruit 2 lecturers and 6 students to (voluntarily) produce plaster casts for the "Touched By Polio" Art Exhibition.
September	Ability First Australia's annual fundraising activity, "Walk With Me", took place on Sunday 9 September. John Tierney and Fran Henke participated in this, Polio Australia's inaugural Walk, raising a total of \$3,622 between them.
October	60 polio survivors and their supporters visited Parliament House in Canberra on Wednesday 31 st October and met with their respective MP's to discuss the three recommendations made in the House of Representatives Standing Committee on Health and Ageing's 2012 Roundtable "Late Effects of Polio/Post-Polio Syndrome - Discussion Paper".
November	Availability and distribution of the "Late Effects of Polio: Introduction to Clinical Practice" resource module developed by GlaxoSmithKline's Medical Team as their corporate volunteer contribution. The resource was launched by The Hon Catherine King MP, (then) Parliamentary Secretary for Health and Ageing.
December	Lyn Glover, Convener of the Gold Coast Post Polio Network, spoke to Ian McNamara - 'Macca' - on his "Australia All Over" breakfast radio program about Polio Australia's "We're Still Here!" campaign. This sparked a flurry of new registrations on the Australian Polio Register.
January	Polio Australia invited to make a submission to the Community Affairs Legislation Commission in relation to the National Disability Insurance Scheme (NDIS), thereby commencing an ongoing campaign to eliminate the discriminatory 65 year cut off.
February	Polio Australia invited to attend the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) NDIS Roundtable held in Adelaide to give feedback on the 65 year cut-off.
March	Polio Australia gave evidence at another NDIS public hearing in Canberra arguing against the 65 year cut off - this evidence was widely broadcast in the media. Also, the "Touched by Polio" Art Exhibition was launched with a fundraising auction of the 35 leg and torso artworks.
April	In collaboration with Polio SA, the fourth Polio Health and Wellness Retreat was held in Glenelg, South Australian, with 70 polio survivors and their spouses/family members attending.
May	Q&A – An Audience with Bill Gates: Polio Australia had the opportunity to be in the 900 strong audience of a special episode of the ABC TV program. Gillian Thomas was able to ask a question of Mr Gates relating to strategies to "get governments to shoulder their responsibility and fund essential post-polio services".
June 2013	Thirty seven 'Campaign Heroes' from across Australia visited Parliament House, Canberra, in a pre-election campaign to rally against the NDIS 65 year cut off. At a morning tea forum, the campaigners were addressed on the topic by Senators Mitch Fifield (Lib), Claire Moore (ALP), and Rachel Siewert (Greens).

Presidents report

by Dr John Tierney OAM

Over the year, Polio Australia has achieved great things with very few resources. Underpinning this success has been the tireless work of our sole staff member, Mary-ann Liethof. Without Mary-ann's dedicated work and "beyond the call of duty" passionate commitment and drive behind Polio Australia's various activities, we would not have advanced as far towards achieving the objectives of our organisation, particularly as we are still one hundred per cent dependent on private funding.

On the vital volunteer side of Polio Australia, Gillian Thomas also like Mary-ann, continues her life commitment to the needs of polio survivors and seems to work round the clock in support of our cause, if her numerous 11:30 pm emails are anything to go by. Behind the scenes Gillian and Mary-ann's work continues on a daily basis to advance our vital work in support of Australia's 400,000 polio Survivors and the three of us have worked as a great team over this year in managing the day to day program of Polio Australia.

This work has been ably supported by Shylie Little, who continued to volunteer two days a week and capably managed our bookkeeping and related administrative duties working out of the Polio NSW office in Sydney. Also I wish to acknowledge the work of volunteers in our Kew Office, especially the support and financial assistance provided to Polio Australia by Jill Pickering. Volunteers on the Management Committee who have provided the guidance essential to the direction of the organisation at our regular bi-monthly meetings and our annual planning gathering in Sydney in December.

Further afield, we are very grateful for the work of our Clinical Advisory Group who also give their time freely. All our volunteers are busy in their own lives but still manage to volunteer between them thousands of hours, to the work of their various support groups, state organisations and to Polio Australia.

Even though so much time is given freely for Polio Australia, to be effective in the long term

its programs and staff needs a much more secure financial base. The year 2013 marks the third and final year of the *Neil Balnaves Foundation* funding. I wish to publically acknowledge our thanks to the Foundation for providing funding over this period, which supported Polio Australia's programs and staffing. Now that this funding is ending, we need to redouble our efforts to raise additional funds for more staff to support Mary-ann as she continues to implement our Strategic Plan.

We engaged Glenn Gardner AM the former CEO of Ability First Australia, to help Polio Australia to develop various fund raising strategies and already some of these are bearing fruit.

The "Walk with Me" campaign started in late 2012 in a small way but has now really become a very promising source of funding in 2013 and in 2014 we would like to see all states holding this event.

Also in 2012 we started the Polio Australia *Patron's Circle*, which now has a number of members who have donated in excess of \$10,000 dollars each to our cause.

Increasingly with fund raising we will be building on the promising start that we have made in developing grassroots contacts with Rotary clubs at the local level. Our consultant Glenn is also exploring ways of working with Rotary at a higher level to rekindle the relationship that existed when Rotary started the *Crippled Children's Associations* in the 1920's.

Our Canberra lobbying activities lifted to another level over the last year with dozens of polio survivors descending on Canberra in both October 2012 and June 2013 at the end of the last parliament. With our white and orange "We are still here" tee shirts on, we certainly made an impact in the "halls of power." We invited the *Parliamentary Friends of Polio Survivors* to a morning tea where we launched an online resource for health professionals "*The Late Effects of Polio: Introduction to Clinical Practice*." We sincerely thank the medical

Presidents report

cont'd

volunteers at GlaxoSmithKline for producing this module.

At both the October 2012 and the June 2013 visit to the Federal Parliament by up to sixty polio survivors, we highlighted the needs of Australia's 400,000 polio survivors in a *National Polio Awareness Campaign*. As part of this we also conducted one on one or group visits to particular MPs to explain the needs of polio survivors and provided them with the excellent blueprint for government assistance that Mary-ann developed.

With our campaign lobbying efforts in Canberra, we now have attracted sixty one MPs who have joined our *Parliamentary Friends of Polio Survivors* group, or agreed to see us, or come along to one of our events, or spoken in the Parliament about the needs of Australia's polio survivors. We are ably supported in this lobbying in Canberra by our five Parliamentary Patrons who have been chosen across Party lines. In this work we are still making great progress in raising the profile of both Polio Australia and this country's 400,000 polio survivors.

Unfortunately this has not led to a direct funding commitment from the Government, but with a n imminent change of government our chances should be better because over the last two years we targeted the key Opposition decision makers with and many of those MPs are expected to hold ministerial and other key parliamentary positions in our policy area.

The previous Government did promise to help, but only if our proposals fitted with their programs. This certainly wasn't the case with the Medicare Locals

nor with the NDIS where 98% of polio survivors are excluded because by 2018 we will be over the 65 age cut off. Much work still needs to be done on what provision will be made for polio survivors in aged care programs in the future.

Other highlights of the year included the *"Touched by Polio"* art exhibition where artists freely gave of their time to paint leg or body casts typically worn by polio survivors after they had contracted polio. These pieces were auctioned off initially at a cocktail party in Kew, which was launched by Senator the Hon. Mitch Fifield who is now the Federal Minister in charge of disability services.

As usual the highlight of the year was the annual Polio Health and Wellness Retreat, held this year in Adelaide. Due to Mary-ann's excellent work, I believe that this outstanding event is world class and of great assistance to anyone who has contracted polio or their carers. If you haven't been to one, don't miss the next one in Sydney in 2014.



Dr John Tierney with Vice President, Gillian Thomas, leading the 2012 "We're Still Here!" campaign at Parliament House

National Program Manager's report

by Mary-ann Liethof



Dr John Tierney's President's Report is such an excellent summary of the year's activities highlighted in this Annual Report, I have decided to dedicate my National Program Manager's Report to broader issues.

Most significantly, I believe I can officially announce that the ongoing existence, and unmitigated success, of Polio Australia is a miracle! When the six state networks first met in 2007 and agreed to establish a national body, I don't think anyone believed that it was going to be so difficult to secure the funding to make it a viable proposition. After all, aren't we living in a developed and relatively wealthy country? Haven't we already identified the need for services for Australia's polio survivors? Isn't it clear that Polio Australia and the state Polio Networks are the only organisations doing any work at all in this area? Don't we have the bipartisan support of a number of federal parliamentarians? So, what's the hold up?

Fortunately, Polio Australia has a small but very dedicated and passionate team of supporters in the form of volunteers and donors - who are

often the same people! There are also the unsung heroes who take every opportunity to raise both awareness and funds for Polio Australia's various activities. As the only paid employee of Polio Australia, I am totally dependent on the good will of all these 'saints' who make the miracle of Polio Australia a reality. I have nothing but respect for so many members of the post polio community, which is why I am still so committed and inspired to continue working to ensure the organisation is relevant and of benefit to Australia's polio survivors and their treating health professionals.

I can't say it's an easy job, performing roles ranging from chief pencil sharpener to representative at federal government roundtable inquiries, whilst coordinating and running the programs mentioned in this Annual Report (including writing and desktop publishing this Annual Report!). But I do like to be 'challenged', and I certainly have no time to be bored.

President John Tierney and Vice President Gillian Thomas are, without doubt, the cogs that keep the wheels turning in the machinations of what is Polio Australia. Without their vision, guidance and considerable personal time and efforts (unpaid), Polio Australia simply wouldn't be able to function. Of course, the governance provided by the Committee of Management representatives is also vital in ensuring that Polio Australia remains connected to the needs of the post polio community through their respective state Polio Network members.

However, additional staff and resources are critical if Polio Australia is to realise its potential in supporting Australia's polio survivors into the future. We desperately need paid and skilled:

- project and research staff to develop a range of new programs and to form partnerships with health professionals to progress the establishment of polio-related clinical services across Australia;
- community development workers to work with the state Polio Networks to run polio awareness and education sessions for

National Program Manager's report

cont'd

community groups, thereby increasing the numbers of polio survivors learning about the Late Effects of Polio; and

- administration personnel to support these activities.

Yet, in spite of the obvious need for 'resources', with all the funding grants I must apply for to support the limited programs we do run, none will pay for 'administration' or 'staff'. So, **who**, I ask, is supposed to do all the work? Oh, that would be **me**, then . . .

I'm quite sure that everyone reading "Polio Oz News" and "Reflections" casts a gimlet eye over

my constant requests for 'campaign heroes' (self-funded, at that!), or donations, or help with finding people or places or things. However, if readers can just imagine seeing themselves in the role of 'available resources' to assist with Polio Australia's work, we will all be making a vital contribution towards improving the health and lifestyle of Australia's post polio community.

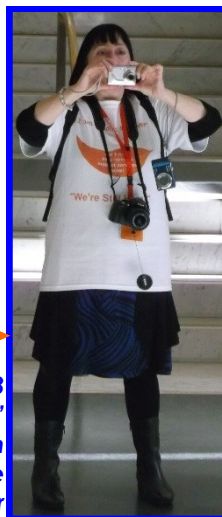
For me - in spite of the fact that the 3 year grant for my salary ends in December 2013 - I look forward to marching into battle for yet another year filled with new challenges and exciting possibilities - such as generating the funds to at least pay my salary!



Heroes of the "We're Still Here!" Campaign - June 2013



2013
"We're Still Here!"
Campaign- Polio
Family Tree



2013
"We're Still Here!"
Campaign
- Mary-ann, the
photographer



2013
"We're Still
Here!"
Campaigners
adding their
names to the
Polio Family
Tree

Fundraising activities



Walk With Me

On Sunday, 9 September, Polio Australia teamed up with Scope at Federation Square, Melbourne to participate in Ability First Australia's annual "Walk with Me" awareness and fundraising activity. This was a first for Polio Australia but we were well supported by Scope.

Polio Australia's National Patron, Dr John Tierney, was in Melbourne on the day to do the walk, and polio veteran, Fran Henke completed a 4 km 'walk' on her scooter around the foreshore in Hastings (Victoria), along with her two dogs.

Between them, John and Fran raised a healthy \$3,622, which is a fantastic effort!

Considering the success of this activity, Polio Australia intends to make it an annual event and, hopefully, grow both the participant numbers and the amount raised.

Touched by Polio

Polio Australia was delighted with the contribution provided by a dedicated group of La Trobe University's Prosthetics and Orthotics lecturers and 1st year students who got together during their term break to create 15 leg and 16 torso casts for Polio Australia's proposed "Touched By Polio" Art/Fundraising Exhibition.

Lecturers Stephanie and Anthony brought along their children Tommy and James Barnard and Noah Francis, and student Lucy also enlisted her children, Amy and Adam, who kindly offered their legs for casting. A fun day was had by all.

We are also very grateful to Bunnings, Hawthorn, who provided packaging material for the casts.



Tommy and Steph Barnard



Priorities One and Two

Rotary International

Polio Australia engaged Funding Consultant, Glenn Gardener, to work on a proposal to rekindle historical links with Rotary Australia and develop a partnership to help address the needs of the thousands of Australians who survived the polio epidemics of the 20th century.

Polio Australia set a goal this financial year of raising, with Rotary Australia's partnership and support, \$10,000 towards the overall cost of providing much needed services. Although this goal was not realised, even more exciting developments are planned for the next financial year.



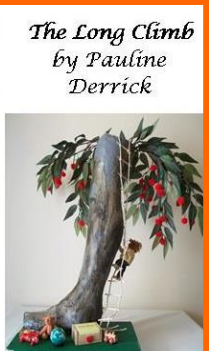
Bound
by Ekaterina
Panorgious



Enduring
by Glenys
Donnelly



*Equal
Opportunity*
by Roslyn Dux



The Long Climb
by Pauline
Derrick

Twenty-four artists who have been 'touched by polio' in some way — survivors, family, friends — contributed to the exhibition to create thirty five leg and torso plaster-cast-based art works. This was quite a 'cathartic' experience for many, as they relived the pain of polio infection and a broken childhood before their casts metamorphosed from clinical 'restriction' to creative 'release'.

The artists' creative expressions were many and varied, and the mediums used included textiles, paint, decoupage, and anything else they could think of!

The "Touched by Polio: from casts to catharsis" Art Exhibition Launch and Fundraising Auction was held on a very hot and windy evening in March, and was attended by around 40 people who braved the unpleasant weather conditions. Thirteen of the thirty five pieces were sold on the night, with a further eight having been sold since, raising a total of \$7,455. A special purpose exhibition website has been created to display the pieces and share the artists' stories: www.polio.org.au

Education and health service promotion

Priorities Two and Three

The Late Effects of Polio: Introduction to Clinical Practice

This year, Polio Australia was able to share a new resource for healthcare professionals entitled the “*Late Effects of Polio: Introduction to Clinical Practice*”.

The resource was launched by the Hon Catherine King MP, Parliamentary Secretary, Health and Ageing (and one of Polio Australia's four Parliamentary Patrons) at Parliament House, Canberra on 31st October 2012.

This resource was designed as an online Module and is accessible to all health professionals through Polio Australia's “*Resources for Health Professionals*” web page.

It is intended that this resource be the first in a series of Clinical Practice Modules for managing various aspects of the Late Effects of Polio. Resources like this “*Late Effects of Polio: Introduction to Clinical Practice*” and the intended subsequent series of Clinical Practice Modules, are vital in assisting health professionals to access concise, well researched, best practice information in the diagnosis and management of polio's late effects.

Polio Australia encourages any health-specific websites linking to it, or even uploading the Module to their own websites. We simply want this resource to be available to as many health practitioners as possible to ensure Australia's polio survivors receive the informed diagnosis and management strategies they so desperately need to maintain quality of life.

It should be noted that Polio Australia received absolutely no funding for this Module. The “*Late Effects of Polio: Introduction to Clinical Practice*” was developed in collaboration with volunteers from GlaxoSmithKline's Medical Team through their corporate volunteering program. The Module was also reviewed by members of Polio Australia's multidisciplinary Clinical Advisory Group, as well as the Committee of Management who represent the six state-based Polio Networks.

By 30 June 2013 there were 2,289 polio survivors on the Australian Polio Register, following the receipt of a further 582 registrations during 2012-2013.

2012		2013	
July	30	January	33
August	19	February	12
September	40	March	13
October	230	April	23
November	61	May	24
December	76	June	21

Obviously, this number is still a drop in the ocean considering the huge number of polio survivors living in Australia with whom we are yet to make contact. For almost half of those registering, this has been their first contact with a polio survivor support organisation.

Without the resources behind us to have regular forays into the media to promote the Register, we nevertheless seize every opportunity for publicise the Register, as well as the late effects of polio and the work of Polio Australia. These efforts are particularly focused during Polio Awareness Month each October (and, as can be seen, was particularly effective in October 2012).

Despite the constraints under which we operate, the Australian Polio Register is now painting a statistically significant picture of not only the number of polio survivors living in Australia, but where and when they contracted the disease (about 20% contracted polio overseas so are not included in Australian polio cases records), the age at which they contracted polio, and whether or not they were hospitalised at the time (18% were not hospitalised while a further 6% don't know - hospitalisation has an impact on whether polio cases were included in official health department records).

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2013 Polio Health and Wellness Retreat

Priorities Two, Three and Four

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 those Retreat participants who followed up with various sized donations to Polio Australia. All contributions were very much appreciated.

This year Polio Australia 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 us to discuss the possibility of U of SA students undertaking a Project based on the Retreat. Of course, we readily agreed. So in 2012, Lee recruited and supervised Vivienne and Alex, who were then completing their fourth year in Physiotherapy.

Under direction, Vivienne and Alex surveyed the needs of Polio SA 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. A great example of the future of our allied health therapists!





Ann (left) and Ben presenting 'Falls' Session



L-R Dr John Tierney (President), Gillian Thomas (Vice President) with Prof Ian Maddocks, Senior Australian of the Year and Guest Speaker



Rooms with a View

What retreat you may ask! There was no retreat, it was advance all the way through, until perhaps by 2.00pm Sunday when the final call was made. The strength of **Body, Mind and Spirit** was well expressed by all participants and presenters. At a personal level I began unsure of what was in it for me...very little thought given to what I might contribute. However both were fulfilled by the time Sunday afternoon came around. I listened to many who expressed issues in their journey that I had not - the pain and attempts to straighten limbs and backs, to say nothing of the pain inflicted by society attitudes to calliper wearing sufferers.

- Ron Blackwell, PolioSA Committee Member

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!! It was a treat to be able to attend.

- Ann Buchan, Neurophysiotherapist and Presenter, SA

I was delighted to meet people from various parts of Australia and hearing their stories of determination as they each grow older and how they are really learning to be patient with their

bodies by taking a slower approach to their daily activities. Also, it's important for our families to be aware of us pacing ourselves according to our health each day of our lives. I really enjoyed getting involved in the singing group which performed on the last day of our Retreat. I was impressed to see the willingness of the people at mid-day, assisting others to place food onto their plates - while the area was crowded with folk who were eager to get lunch! The speakers were inspiring and so willing to listen to our comments between session times. The view from my room was delightful, so restful. I could have stayed a month. It came at the right time in my life, as I had pins in my middle finger on my left hand, which is the one I write with. Yes, it made it very difficult to take notes, and even cut up food. But it gave me time to relax from my busy lifestyle. I have since heard from many who attended the weekend - yes, new friendships were created. Thank you!

- Jo Gordon, SA Participant

I must admit, on my arrival at the Stamford Grand Hotel, I was somewhat unprepared for meeting so many polio's in one place. I guess this was an environment I'd not experienced since childhood. I very soon found my place and for a change was not the odd one out with a handicap, as I know we are all so familiar with. I was just starting to get myself organised with the somewhat hectic schedule, sessions, meal times etc, when the time came to pack for home. The friendships made, shared experiences and fun times will not be easily forgotten, and the closing microphone pass around was very touching, I must confess.

- Douglas Chugg, Tas Participant

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. 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.

- Sylvie Cleret and Marc Adams, SA Participants

2012-13 Lobbying campaigns pictorial

Our Parliamentary Patrons



- Mark Coultan MP (National)



- Jill Hall MP (ALP)



- The Hon Greg Hunt MP (Liberal)



- The Hon Catherine King (ALP)



- Senator Rachel Siewert (Greens)



2012 Campaigners with (then) Prime Minister, Julia Gillard



The Hon Greg Hunt with Fran Henke



2012 Campaigners with Sussan Ley MP (Lib)



2013 Campaigners with the Hon Philip Ruddock MP (Lib)



2012 Campaigners with Adam Bandt MP (Greens)

No access to the NDIS

Priority Three

Inquiry into the National Disability Insurance Scheme Bill 2012

Excerpt from Polio Australia's Submission

29 January 2013

Polio Australia congratulates the Government on this initiative and welcomes the benefits it will bring to people with a disability in Australia. The fact that the Scheme aims to provide for the needs of all people with disability, regardless of the cause of the disability is particularly important. To date there has been little support for those whose disability arose from medical conditions or the support was inconsistent and often dependent on very specific funding programs. Many, perhaps the majority, of Polio survivors 'fell through the cracks' of all programs and have had minimal assistance.

We fully support the aim of the NDIS to "support the independence and social and economic participation of people with a disability".

Relevance of the NDIS to polio survivors

The key aspects of the NDIS bill that are of particular relevance to people with the LEOP are summed up in the following phrases:

- *Participants develop a personal, goal-based plan with the Agency, and how reasonable and necessary supports will be assured to participants.*
- *Will fund reasonable and necessary services and supports directly related to an eligible person's individual ongoing disability support needs;*
- *Will enable people with disability to exercise more choice and control in their lives, through a person-centred, self-directed approach, with individualised funding.*

Each polio survivor has a different set of disabilities or limitations and different personal circumstances. There are commonalities, which mean that services need to be provided by personnel who have knowledge of LEOP. Unfortunately this factor is often not met. The opportunity to have a personal plan and funding to access appropriate services and to ensure co-ordination between services would be greatly valued by most polio survivors.

Polio survivors lack of eligibility for the NDIS

The summary statement for Chapter 2 of the Explanatory Memorandum clearly states that "Chapter 2 sets out the general supports and assistance, including funding, that the Agency can provide to **all** people with disability and other individuals and organisations to enable them to support people with disability". Unfortunately for many polio survivors the concept of **all** people with disability is a misnomer as the eligibility requirements will rule almost all people with LEOP out for any assistance. A very serious concern for Polio Australia and the state-based Polio organisations is that Polio survivors will not be eligible for NDIS provisions on the grounds of age.

It is acknowledged that in the design of the NDIS it was considered that age care programs would meet the needs of those aged 65 and over. It can also be assumed that it was considered that disabilities, which are specifically related to ageing, might be more appropriately provided for under aged care programs. Polio Australia has been told that after sixty-five years of age, people with the LEOP can then access services in the aged care sector. The problem with this is that currently **there are no specialist LEOP services for people over sixty-five in the aged care sector**. As the provision of services that people with the LEOP require over the age of sixty five are grossly inadequate now, it would be a tragedy if this situation was compounded by an NDIS scheme that excluded Polio survivors, one of the largest and most needy disability groups in Australia.

The NDIS aims to prevent people experiencing the problems and deprivations that these people have either endured or overcome to the best extent they could with little or no assistance. The NDIS should enable people with a disability from now on to have a greater chance of a fulfilling life.

Most Polio survivors meet the eligibility requirements in that their disability is permanent and their support needs are "likely to continue for the person's lifetime".

Our request is that those whose disability pre-dates the introduction of NDIS is long-standing and permanent should not be excluded on the grounds of age while aged care programs cannot meet their special needs.

Polio Australia's existing programs

Community / Patient Education

Late Effects of Polio Self-Management Residential Program

Polio Australia holds an annual Late Effects of Polio Self-Management Residential Program (also known as "Polio Health and Wellness Retreats") for up to 70 polio survivors and their families/carers which have addressed self-management strategies for the post-polio body, the healthy mind and the spirit. These Retreats are held in a different state each year to ensure polio survivors around Australia have access to this vital information.

Since 2010, 4 Retreats have been run in April each year: NSW (2010), Vic (2011), Qld (2012), and SA (2013). For each of the 4 days of the Retreats, several local health and other practitioners were sourced and invited to facilitate presentations. Most required additional education on the LEOp/PPS, but were all well acquainted with the issues by the completion of their sessions, thanks to exposure to so many polio survivors in one place. This 'crash course' in the LEOp/PPS now provides them with more effective strategies to assist other patients/clients.

Polio Awareness Month

Each October, Polio Australia coordinates awareness-raising through its annual Polio Awareness Month campaign. Known polio survivors are contacted and their stories are provided to the print media and radio stations to broadcast the message that "We're Still Here!" and that there is information and support from Polio Australia and Networks for people who are experiencing the LEOp/PPS and may not be aware of the condition.

In 2012, the campaign culminated in a mass visit to Parliament House with 60 polio survivors and their family members and friends from across Australia met with their local MPs to discuss their needs.

In addition, all state-based Polio Networks are encouraged and supported to generate local

media interest during October, with the aim of potentially reaching new members. Polio Awareness Month activities are also promoted via Polio Australia's publications and website.

Educational Presentations

Polio Australia currently organises speaking engagements at a variety of service clubs, such as Rotary, as a source of promotion and potential funding revenue. Polio Australia also seeks opportunities to speak to groups within the community who might be experiencing the LEOp/PPS.

Publications

Since October 2010, Polio Australia has published its e-Bulletin, "Reflections", eight times a year.

In February, May, August and November, "Reflections" is incorporated into our subsequent quarterly e-Magazine "Polio Oz News", which was introduced in June 2011.

Both these publications are a rich source of information for readers, which is obtained from a wide range of sources including material from health professionals, stories, reports on Polio Australia's activities, government initiatives, current affairs, and more.

Both "Reflections" and "Polio Oz News" are compiled, edited, published and distributed electronically by the National Program Manager.

Email distribution of these newsletters is currently at 1590 (and growing), including 200 international organisations and individuals. All editions are also uploaded to the website for general viewing.

Websites

Through volunteer efforts, Polio Australia launched its main website in 2010, following several unsuccessful attempts to secure government or philanthropic funding. The website has been promoted through Polio Australia's publications and has a high rating with Post-Polio Health International. The website attracts an average of 235 views per day. Two additional websites have since been created to promote specific activities.

Polio Australia's existing programs

Australian Polio Register

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. Despite limited resources to promote the Polio Register widely in the community, Polio Australia has achieved remarkable results to date.

It complements Recommendation 1 of the "Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome".

Education for health professionals

Clinical Advisory Group

To help achieve its goals, Polio Australia has established a Clinical Advisory Group (CAG) comprising open-minded health care professionals who are experts in their field and have knowledge about polio and its late effects.

The aim of the group is to advise on quality information and best practice service provision across Australia, incorporating appropriate diagnosis and management of the LEO/PPS.

The Clinical Advisory Group provides recourse to Recommendation 2 and 3 of the "Discussion Paper on the Late Effects of Polio/Post-Polio Syndrome".

Late Effects of Polio: Introduction to Clinical Practice Resource Module

In October 2012, Polio Australia launched a new online resource module at Parliament House, Canberra titled "The Late Effects of Polio: Introduction to Clinical Practice".

With no funding forthcoming from government or philanthropic sources, this module was developed and produced thanks to GlaxoSmithKline (GSK) Australia's corporate volunteer program. The reference sources, content and structure of the resource module was guided by Polio Australia and written by GSK's Vaccine Department's Medical Team.

Potential program development

Polio Australia has plans, dependent on additional resources, to develop further mechanisms and services to enable health professionals to perform best practice in the management of their polio patients. These include:

- the establishment of a website specific to health professionals to be used as a resource for widening the range of health professionals accessing information on diagnosing and managing the LEO/PPS for their patients;
- the production and distribution of videos for health professionals via the website as part of their professional development and/or continuing medical education;
- the publishing of articles in discipline-specific Professional Journals, widening the range of health professionals accessing information on diagnosing and managing the LEO/PPS for their patients;
- formulating and providing blueprints for model polio clinics to be established in each state and territory, incorporating public and private sectors, rural satellites, and remote consultation for implementation across Australia; and
- Identifying and stimulating research projects in to the management of LEO/PPS.



Funding sources 2012-13

Key Contributors

\$101,750

Balnaves Foundation

3 years funding for full-time National Program Manager (from Jan 2011 to Dec 2013)

Jill Pickering

Personal donations towards the cost of operating expenses

Dr John Tierney OAM

Personal donations to support lobbying activities

Monique Liethof

Personal donation towards the cost of operating expenses

Project Funding Grants

\$33,000

GlaxoSmithKline Australia

- Financial contributor to the 2013 Late Effects of Polio Self-Management Residential Program (Polio Health and Wellness Retreats)
- In-kind contribution to the 2012/13 Polio Awareness Month media campaigns
- In-kind contribution to the "*Late Effects of Polio: Introduction to Clinical Practice*" resource module launched in 2012

The Marian and EH Flack Trust

Financial contributor to the 2013 Late Effects of Polio Self-Management Residential Programs (Polio Health and Wellness Retreat)

Mary Mackillop Foundation

Financial contributor to the 2012 AGM/ Strategic Planning Meeting

Fundraising Activities

\$23,827

Rotary International = \$1,750

2012 "Walk With Me" Activity = \$3,622

Patron's Circle = \$11,000

"Touched by Polio" Art Sales = \$7,455

General Donations

\$6,839

Health & Wellness Retreat Donations

\$6,565

Merchandise Sales

\$727

Membership

\$600 pa

Membership fees are paid annually by the six state-based polio networks on Polio Australia's Committee of Management

In Kind Support

Peter Roebuck (FCA)

Pro bono auditing of Polio Australia's accounts

Genuine Print

Pro bono production of business cards, brochures and posters

Rob Foster (UK) and Michael Simpson (USA)

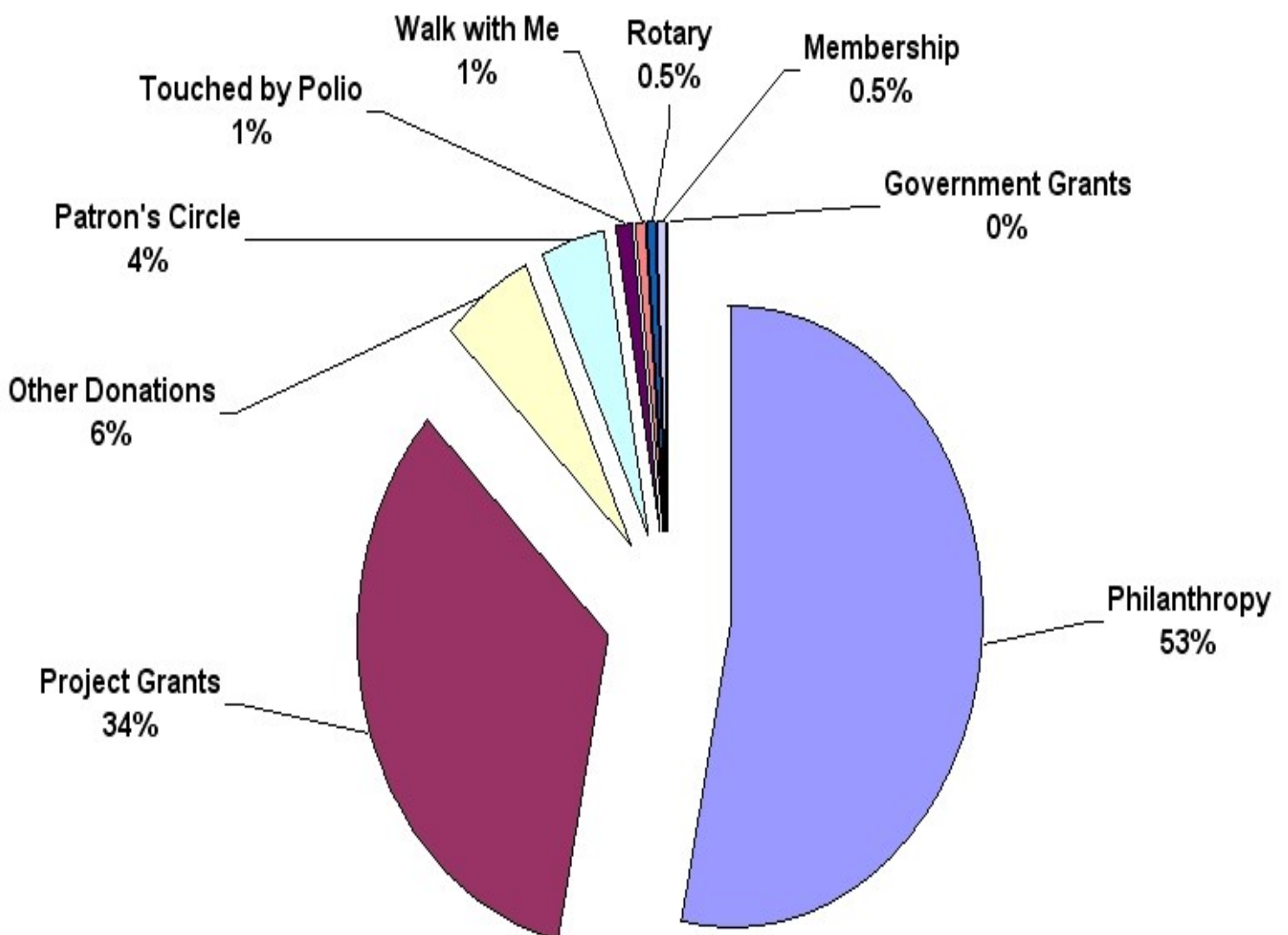
Pro bono assistance with website

Funding sources 2012-13

cont'd

Polio Australia would like to thank all the individuals and organisations who gave donations from 1 July 2012 to 30 June 2013.

Thank you for investing in us to make a difference – every dollar supports Australia's polio survivors.



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 issues an official receipt for all donations received.

Our volunteers

In addition to those mentioned below, the nature of not-for-profit charities is that there are numerous people and organisations quietly providing support in many, many ways, and we sincerely thank each and every one of you for your contribution.

Business and Web Manager



Gillian Thomas

Gillian works day and night to ensure Polio Australia meets all its business and financial responsibilities. Using her considerable technical expertise, she designs, populates and manages Polio Australia's three websites, and provides input across all program areas based on her expert and personal knowledge of polio and its late effects.

Gillian has also volunteered at Polio NSW for 25 years, and was elected the Network's President in 1997, a position she still holds. Gillian was Editor of the Network's quarterly newsletter *Network News* from 1989 to 2012.

Gillian's passionate belief in the need for a national voice for polio survivors culminated in the highly successful meeting of all Australian State Polio Networks in May 2007 and the unanimous agreement to form Polio Australia. In 2008, she was elected Polio Australia's inaugural President. At the 2012 Annual General Meeting, having served two consecutive terms as President and being constitutionally ineligible to re-stand at that time for this position, she was elected as Vice President.

Lobbyist



Dr John Tierney OAM

Dr John Tierney OAM is Polio Australia's National Patron, and was elected President in December 2012.

Since 2007, John has taken a delegation to Canberra on a semi-annual basis to lobby for special funding for the half a million Australians experiencing LEOP. John has done this in his capacity as a pro bono government relations consultant to Polio Australia.

Previously John gave 14 years of distinguished service to the Australian Parliament, where he served as Senator for NSW. In the parliament, as a polio survivor, he took a passionate interest in the area of disability. John was a special parliamentary adviser to the Minister for Community Services on disability matters. Prior to entering Parliament, John was a Senior Lecturer in Education at the University of Newcastle until 1991.

Thanks to John, Polio Australia has made substantial progress in making the government and the parliament aware of the late effects of polio, although we still haven't received any dedicated funding. John's commitment is to continue lobbying until we do!

Administration



Jill Pickering

(Kew, Victoria Office)

Jill commenced volunteer work one day a week with Polio Australia in February 2011. She assists with tasks including keying in data for the Australian Polio Register, and compiling and summarising feedback information from the Health and Wellness Retreats for reporting purposes.

Previously, Jill worked in several roles using her Occupational Therapy skills before retiring in 2000 due to limitations caused by post-polio syndrome. She then volunteered for 10 years at Polio Network Victoria before joining Polio Australia. Jill is also the current President of Post-Polio Victoria.



Shylie Little, Administration and Bookkeeping Volunteer
(Parramatta, Polio NSW Office)

In her two volunteer days a week Shylie assists with banking, scheduling payments, bookkeeping, and a myriad administrative tasks which free up time for both Mary-ann and the Management Committee. We are grateful for Shylie's dedication to polio survivors.

Special thank you

From time to time, Polio Australia co-opts volunteers with particular expertise for special projects.



Brian O'Reilly
(Kew, Victoria Office)

Brian began volunteering one day a week in May 2013, and assists with the preparation of funding applications.

Brian has worked and studied in the public, private, health, and education sectors, and is currently studying Health Promotion.



Graduate Physiotherapists, **Alex Daniel** (left) and **Vivienne Maxwell**, provided invaluable support at the 2013 Polio Health and Wellness

Retreat held in Adelaide. Following on from their final year University project in 2012, surveying the needs of PolioSA members in the lead up to the 2013 Retreat, Alex and Vivienne were able to realise all their efforts when they volunteered as willing and able assistants over the weekend. They did a remarkable job!

Our Social Network 'Champions'

Ella Gaffney (below left) from Mudgee in New South Wales, and **Lyn Glover** (right) from the Gold Coast in Queensland have continued their good work as Polio Australia's social network 'Champions'. Ella and Lyn keep Polio Australia's Twitter followers and Facebook visitors up-to-date with the latest news, as well as whatever snippets they find of interest which they share with our wider social networks.



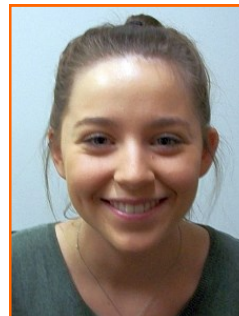
2012 and 2013 "We're Still Here!" Campaign Lobbying Team Volunteers



Denton Trieu

For the 2012 Campaign, we were fortunate to have the volunteer assistance of Denton, a 4th year Bachelor of Business (Marketing) student from Monash University, to prepare, distribute and follow up Media Alerts profiling various Campaign Heroes.

Denton was also responsible for social media activity on Polio Australia's Facebook page and Twitter account, as well as instigating and tracking the online Petition. Denton was recruited and mentored by GlaxoSmithKline's Manager Corporate Affairs and Patient Advocacy, Ken Griffin.



Edwina Toohey

Polio Australia also acknowledges and thanks Edwina, a 1st year Media and Communication student at Swinburne University of Technology, for working on the 2013 campaign with us.

Edwina was kept busy drafting Media Alerts and uploading information onto a new website specifically created for the "We're Still Here!" campaigns.

Edwina was also mentored by GlaxoSmithKline Australia's Ken Griffin, who has been a wonderful support over the years.