

POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

Polio Australia was delighted to be given the opportunity to field a team in Northcott's "Walk With Me" fundraising event held in Parramatta on Friday 13th September. The day dawned cool, but reasonably sunny and, thankfully, dry. Polio Australia's "Parramatta Promenade" team (*comprising Polio NSW members and friends – some are pictured below*) have raised over \$8,000 to date towards Polio Australia's vital work in support of polio survivors and their families – in other words, in support of YOU! This is a magnificent effort, and it's not too late to donate – just visit www.parramatta2013.everydayhero.com/au/parramatta-promenade.



I hope to see many members at Polio NSW's 25th Annual General Meeting to be held at Burwood RSL on Saturday, 30th November. Our Seminar speaker following the meeting will be Anne Reddacliff from The Black Dog Institute who will be presenting on "Breaking Down Depression and Building Resilience". Don't miss it! Our Annual Report will be issued in November. Until then, we hope you enjoy this bumper *Network News*!

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Polio Awareness Month - We Need Your Help!

By Anne Buchanan, Publicity Officer

October is almost upon us and brings with it Polio Awareness Month. In other words, it is that time of year when we, as an organisation, work to promote awareness within the polio community as well as to remind the medical and general community that polio is still around, although in Australia it now presents itself in a different form for the majority of polio survivors.

To help raise the profile of polio and its late effects, you will find a poster included with this *Network News*. Flyers are also being printed – hopefully they'll make this mailout (if not, they'll be sent to you next time). Your Management Committee would be grateful if you could put this publicity up in appropriate locations where you live and/or in places you visit. Suggestions are medical centres, doctors' surgeries, pharmacies, community noticeboards, and even some shops (eg Gloria Jean's) have noticeboards. The choice is entirely yours.

We would also be interested to hear from anyone who thinks of an unusual site to place a flyer or poster, or who has an interesting experience when "spreading the word". It could be that your idea this year may be useful to someone else to use next year. Feedback is never a bad thing and is always most welcome. It helps your Committee do a better job for you, so please tell us about your successes, your difficulties, and your suggestions with this promotion. Our posters and flyers can also be viewed on, and downloaded from, our website at <www.polionsw.org.au/publicity> – please feel free to print and distribute copies.

The Committee thanks you for your help and support with our publicity efforts not only during this annual awareness activity, but all year round, and wishes you every success.

Dr. Susan Perlman Speaks to Support Groups

Dr Susan Perlman gave her annual state of Post-Polio Research presentation to Orange County on Sunday, May 19, in Villa Park. A copy of the presentation can be found on the <<http://PPsupportoc.org>> website for those who wish to review it in greater detail. Reprinted from: Post-Polio Support Group Newsletter, July 2013.

Because of aggressive vaccination programs throughout the world, we grow ever closer to a time when wild polio is no longer the virulent epidemic it once was. The resistance to aid workers and a fear that the vaccination workers are channels for espionage has made the programs in these three countries very difficult and dangerous.

Dr Perlman gave a rundown on the studies which were implemented or findings reported during the past year, some of which were follow-on studies to those discussed in past addresses. The efficacy of IVIG (Intravenous immunoglobulin) treatments continues to mount and the results show far longer benefits than were shown in prior studies. It appears that multiple infusions of the IVIG over several days can produce results lasting a year or more. This is very encouraging. However, the price for such treatments is still very high. As the evidence mounts as to the benefits, it will be much easier to make a case to insurance companies that the benefits outweigh the costs. It does not require continuous infusions to demonstrate positive results.

Some of the studies identified significant risk factors for individuals who were likely to suffer from the late effects of polio. One study indicated that females are more prone to develop

the condition, which other studies dispute. They all seem to agree upon the fact that the level of destruction of nerves in the initial acute stage was a strong factor in the development of PPS. Other factors suggested are age at the onset of the acute phase.

In addition to the research studies implemented or reported over the past year, Dr Perlman included two case studies that were indicative of new information about the potential late effects of post-polio on patients. The first covered concerns of anesthesia on post-polio patients and her recommendation that even minor surgeries that include minimal amounts of anesthesia be done in hospital rather than as outpatient procedures, as a precaution. There is ample evidence available that such procedures can result in prolonged unconsciousness and she will no longer agree to such procedures for her patients unless they are admitted at least overnight for observation and monitoring.

The second case study involved bladder muscle failure of autonomically enervated muscles, which in the past have not generally been associated with post-polio syndrome. However, after a review of the literature over several decades, there is evidence, albeit rare, of such muscular failure which affects the bladder or its support system causing the condition described.

These case studies generated considerable discussion. Much of it focused on individual experiences, mainly negative, with anesthesia for even simple dental procedures, as well as other usually benign routine periodic health checks such as colonoscopies. It is advised that should your physician recommend such a procedure, he and his anesthesiologist be given a copy of Dr Calmes article on the deleterious effects of anesthesia. ***(A copy of Dr Selma Calmes article is included with this issue of Network News as a handout to give to your medical practitioners)***

The discussion also included experiences with physicians who have limited knowledge of post-polio or insensitivities to the special requirements that might be necessary to treat us. There are occasions when it might be imperative to seek out someone who has greater knowledge of the condition, which is always preferable. However, should you feel it is incumbent to continue with a physician who has limited experience or knowledge of post-polio, there is enough material online that can provide a minimal knowledge base for any doctor. In California, we are especially fortunate in that there is a recommendation by the state medical board for basic information requirements for treating such patients. That requirement to be minimally informed on the condition can translate into increased liability for adverse effects during treatment of post-polio patients. Not all states have the same requirements that California does.

One final caveat expressed by Dr Perlman is that however many specialists you are seeing, it is imperative that you have one person who is your 'gatekeeper' coordinating your care with all health providers so that there are no conflicting treatments or medications and that everyone knows and understands the desired outcomes and protocols being implemented. It can be your general practitioner or one of your Specialists, but it should be someone with whom you are comfortable. You should feel you can be very candid and open with this person and confident that they are the leader of your 'team'.

Disclaimer by the PPSG of OC and Rancho Los Amigos Support Group: Information provided in our newsletters and at our meetings is provided solely as information. It is not to be taken as an endorsement of any product, individual, medication, or treatment. If you have personal medical problems, please consult your own physician knowledgeable in the late effects of polio. Unless otherwise stated, the articles in this newsletter may be reprinted provided that they are reproduced in their entirety, and the author, the original source, and the PPSG of OC and/or the Rancho Los Amigos Support Group are acknowledged in full.
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DisabilityCare Australia - Some Questions Answered

By Tricia Malowney

Reprinted from the Eastern Polio Support Group Inc. Newsletter, July 2013 – polioeast@gmail.com

Many people have been asking for information about DisabilityCare Australia – who is in, who is out, what's in it for me? My priority has been on ensuring that the needs of all Australians with disabilities are met, regardless of diagnosis, and it is important to note that Australians with polio are not the only Australians who are affected by the rules.

The following information has been provided by Lesley Hall, the CEO of the Australian Federation of Disability Organisations, which has been at the forefront of ensuring that our needs are met.

Following is the response from DCA regarding questions that were raised at the members meeting on the rollout of the NDIS.

People over 65

People over 65 will be able to access the NDIS if they have “previously accessed supports”. What exactly will this mean, especially for people who have an episodic need for supports (and, my own addition, for people who can't access supports right now because there aren't any or the waiting lists are too long)?

People who are DisabilityCare Australia participants can choose to remain in the scheme on turning age 65.

Eligible participants who do not have ongoing funded supports as part of their current plan may still be considered to be participants if they meet eligibility for the scheme and can therefore choose to remain in the scheme on turning 65. For example, a participant who may have had funded supports such as home or vehicle modifications in their plan previously (episodic supports) but does not have any ongoing funding in their current plan is still considered to be a participant if they meet all of the access requirements.

People who had been participants in the scheme but exited the scheme because they no longer met the access requirements will not be eligible to re-enter the scheme after 65. For example, a child who received early intervention to address a developmental delay, who after receiving that early intervention no longer had any ongoing care and supports needs and exited the scheme, would not be able to access the scheme as a 65 year old.

People who 'can't access disability supports right now because there aren't any' (not current disability service clients) will not be able to access the scheme if they are 65 years or over.

People who are currently on waiting lists for State/Territory disability services will enter the scheme in launch locations as follows:

- People with disability on state-based waiting lists in Victoria and Tasmania will be treated as existing clients and will access DisabilityCare Australia in the first tranche.
- In South Australia they will be phased in as existing clients with their age cohorts so will access the scheme at the same time as their peers.
- In NSW, these individuals will be treated as new clients and can access the scheme at any time.

The numbers on these waiting lists, particularly in Victoria, have expanded since the initial agreement to phase them.

Access requirements

Can the agency meet access requirements for private meetings where necessary?

Any person requiring accessibility or other assistance (for example, live captioning or Auslan interpreters) can be made available at meetings. If you require an interpreter or other supports please contact the organiser of the meeting for DisabilityCare Australia and they will organise and pay for the relevant assistance.

One of the Commonwealth ‘in kind’ supports is the National Auslan Booking Service. Does this mean that in the launch sites people who need interpreters for a range of things will only be able to book them through NABS?

No. NABS will continue to provide the existing contracted service and this can be recognised as an in-kind for DisabilityCare Australia participants in launch sites.

Guidelines for assessment

A fact sheet on planning and assessment is currently being prepared and will be on the DisabilityCare Australia website shortly.

Funded Service Providers

What exactly constitutes a ‘funded service provider’ for the purposes of transitioning people across under the intergovernmental agreements?

This was particularly raised in terms of vision impairment, which isn’t mentioned under the IGAs at all and which often means people access supports sporadically.

Funded Service Providers are those which have been identified by jurisdictions as providing a contribution to the scheme over the launch period.

If everyone from a single service provider is transferred across at the same time, will they be stuck with that service provider? What steps will be taken to ensure people aren’t pressured to stay where they are in the lead up to the transfer?

The launch will focus on increasing choice and control for participants of the scheme. Previous moves to individualised funding in other jurisdictions has demonstrated that people choose to keep their existing supports initially but overtime may vary their choice to include alternative supports that meet their needs. As some programs are being offered in-kind there may not be as wider choice as there will be as launch progresses. However, plans can be reviewed if required over time.

People with existing disability who have a catastrophic accident

The exact arrangements for eligibility DisabilityCare Australia participants who have a catastrophic accident will depend upon who is responsible for assisting the person in respect of their catastrophic injury. Options could include DisabilityCare Australia continuing to provide all of the person’s disability supports and seeking reimbursement from the responsible third party, or DisabilityCare Australia providing support for the pre-existing disability and the third party providing support in relation to the catastrophic injury (which would obviously need to be coordinated). Regardless, the overarching principle will be that DisabilityCare Aust. provides the care and support that a person needs when they need it.

Mobility Allowance

DisabilityCare Australia participants (including those that stay in the scheme after age 65) will not be able to access Mobility Allowance, following receipt of a funded package, as all of their reasonable and necessary travel costs will be met by the scheme. People currently receiving Mobility Allowance will need to relinquish it when they receive a funded package through DisabilityCare Australia. Mobility Allowance will still be available for people who

are not able to access DisabilityCare Australia provided they meet the eligibility criteria for that payment.

Rural and regional services and CALD services

DisabilityCare Australia's funding arrangements will be flexible enough to be able to address unique needs. Block funding may be appropriate in certain circumstances provided it does not overly limit an individual's choice and control. There will also be some flexibility around who can be engaged to provide supports, but will be balanced by the need to provide safeguards for the person with disability (particularly if they are vulnerable). People will generally not be able to employ family members, but it may be considered in exceptional circumstances.

Data Collection

DisabilityCare Australia's will be collecting extensive data in order to meet the accountability requirements of the Standing Council on Disability Reform and also to manage scheme performance. This will include information about the reasons why people were not able to access the scheme.

Information about the Scheme

People were also keen to have this information so they can pass it on through their networks. It was stressed that there should be information about what the delays between applying and finding out whether you're 'in' will be.

The website is being regularly updated and recently more information for participants was put onto the web. Products are being developed that will provide a higher level of detail about access processes. The MyAccess checker is now available on the website.

For more information, the website address is <www.disabilitycareaustralia.gov.au> or you can call on 1800 800 1100.



Have You Forgotten? by Anne Buchanan, Publicity Officer

It has been drawn to the attention of the Management Committee that many of our members forget to carry their Medical Alert Card with them, and forget also to show their copy of the publication "Hospital, Medical and Dental Care for the Post-Polio Patient - A Handy Reference" to the various health service providers they attend.

It is wise to remember at all times that it is in your best interest to make all your health care providers (including dentists) aware of the Late Effects of Polio and the many and varied special needs which may result. As we all know only too well, a large number of health professionals know little or nothing about polio and its late effects, so it is up to each of us to ensure that every person treating you knows as much as possible about polio and its late effects before they commence treatment of any type.

Perhaps you have moved residence and have had to change your service providers, perhaps the Clinic you attend has new staff, or even your long-term health professional could do with a gentle reminder and update regarding your special circumstances. As you are reading this, could it be that you are thinking to yourself "*I wonder where I have put my Medical Alert Card and/or Handy Reference*"?

Whatever your particular situation, you will find "A Handy Reference" enclosed with this *Network News* to help you to easily distribute the appropriate information to all the health professionals involved in your care. Polio Australia with the input of all State Polio Networks is currently developing a national Medical Alert Card (*will in due course replace the current Polio NSW card*) and we will issue you one as soon as they are available. In the meantime, if you have misplaced your existing NSW Medical Alert Card, the Polio NSW Office still has a limited stock so contact George and his team to obtain one. And, most of all, don't forget to use these important resources!

My Aged Care

The purpose of My Aged Care is to provide people with information about the aged care system and how to access services.

What are the benefits?

It is the one point of contact for older people, their families and carers wanting clear, consistent and reliable aged care information. It will also provide accurate and consistent information on healthy and active living, and a fast way for people to find service providers near them. The My Aged Care national contact centre will directly transfer calls to service providers who may be best placed to help. Where appropriate, calls will be transferred to the Translating and Interpreting Service, or to the National Relay Service.

When will My Aged Care Commence?

My Aged Care commenced from 1 July 2013. You can contact the My Aged Care national contact centre on **1800 200 422**. You can also visit <www.myagedcare.gov.au>

Hours of operation:

8 am to 8 pm Monday to Friday and 10 am to 2 pm Saturday (local State and Territory time). Closed on Sundays, and national public holidays.



**Serenading
50's, 60's, 70's
SHOW**

**FRANCESCA
BRESCIA** **KRISTY
LEE** **LISA
BUDIN** **ROSEANNA
GALLO** **GEORGE
VUMBACA**

POLIO NSW FUNDRAISING BENEFIT CONCERT
In memory of Mary Leclair (Lisa Budin's Mum)
SATURDAY 26TH OCTOBER 2013
PARRAMATTA LEAGUES CLUB
11-13 O'Connell St, Parramatta
SHOW STARTS 7PM
Tickets: \$28.00 book through Lisa Budin 0430 050 548 or email: lisabudin1@hotmail.com
Or through Roseanna Gallo 0418 692 410 email: roseanna@rgmusic.com.au
Or purchase tickets through the Parramatta Leagues Club PH: 8833 0777

Have you booked your tickets yet for the Polio NSW Fundraising Benefit Concert on Saturday, 26th October 2013? Phone and book via Lisa Budin 0430 050 548 or the Polio NSW office on 02 9890 0946. Tickets cost only \$28 and payment can be made on the night, but you must book – be sure to get in early as there are a limited number of tables.

So, please make every effort to gather your family and friends together and attend this concert in support of Polio NSW – and have a great evening at the same time!

Accessible ship sets sail for first trip to Oz

Written by Mary Corbett, First Printed in Spinal Injuries Association's
The Advocate Magazine, May-June, 2013. (theadvocate@spinal.com.au)



Lord Nelson is the first accessible tall ship to sail around the world and you can join as a crew member when she makes her first visit to Australia this year.

She is the first accessible ship to sail around the world and she's on her way down under.

Built in England in 1986 and officially launched by Prince Andrew and Sarah Ferguson, the 55-metre square rigger is taking part in the Norton Rose Sail the World Challenge.

It is a journey of more than 80,000 kms designed to promote equality and inclusion at every port of call. During the 23-month voyage, the vessel will make four equator crossings, covering 30 countries in all the seven continents. At each port of call, locals get the opportunity to join the ship as members of the voyage crew for the next leg.

Josephine Hall from Jubilee Sailing Trust, a charity which owns and operates the Lord Nelson, told the Advocate: *"We shall be arriving in Fremantle on 20 July. We aim to sail with 50 percent people with disabilities and 50 percent able-bodied crew and they work together as a pair and then within a team (watch). We can take up to eight wheelchair users, four visually or hearing impaired and those aged 16 or older with no upper age limit"*.

"We are really looking forward to visiting Australia and hope that some of your members will be able to sail with us on this unique experience."

The Lord Nelson was a pioneer in the sailing community. She was designed and built to enable people of all physical abilities to sail side-by-side on equal terms. Since her launch, she has taken 37,000 people to sea, 14,000 of whom were people with physical disabilities, including 5,000 wheelchair users. The permanent crew is highly professionally trained and medically skilled. On each voyage, 40 trainees with all kinds of backgrounds and abilities can help crew the vessel.

It is built to enable people of all physical abilities to take an equally active role in sailing her. Some of the features on board are Braille signs, lifts between decks, wide aisles, vibrator pads fitted to the bunks to alert crew members in the event of an emergency, power-assisted and 'joystick' steering and a speaking compass. There are eight spacious cabins, suitable for wheelchairs, fitted with seats and adjustable basins in the shower.

Spinal Injuries Association Ireland member James Walsh, from Cork, who has L2 incomplete paraplegia and walks with the aid of a crutch, took part in one of the early legs of the journey, from Dublin to Greenock, Scotland over six days.

He was one of 37 temporary crew members for the trip. Upon joining the ship, there was a one-hour crew briefing by the first mate and subsequently James was assigned to the aft starboard watch. As a watch member, he was required to carry out the full duties of a

watch member, for example, ship watches at various times throughout the voyage, one of which was the middle watch from midnight to 4 am; 24 hours of duty as mess man to assist the cook in preparing dinner, breakfast and lunch and also serving up the meals to his fellow crew members.

Each crew member with a disability is partnered with an able-bodied crew member. The partners, apart from being crew members, are there to give any assistance when requested. James' partner was Paul Goodall and during the voyage, they formed a great bond of friendship.

The ship left from Dublin city centre, where it was berthed with a number of other ships which had taken part in a tall ships race. All the ships sailed in flotilla down the River Liffey. James said it was a wonderful sight "*with all sails out and a blue sky*".

The highlight of the trip for James was when he climbed the rigging up to the crow's nest. He described it as an unforgettable experience, one that will remain with him for the rest of his life. James says that the whole voyage was one of the most exhilarating experiences he's had. He learned many new skills, especially working with ropes and sea navigation. He does admit it's not for the faint-hearted but he says, "*If you're up for it, most definitely go for it*".

The Jubilee Sailing Trust subsidise the costs on every voyage to make their tall ship adventures as affordable as possible. They also offer help to those who might struggle to afford the full cost.

They are currently organising day sails and open days for their Australian visit. On day sails, you can try your hand at helming the ship and setting the sails, and enjoy freshly-cooked food straight from the galley. Children from as young as 12 can join in, making it a great day out for families.

For more information or to book a place on board, log onto <www.jst.org.uk>, or phone +44 (0) 23 8044 9138 Monday to Friday, 9am – 5pm (GMT), email <info@jst.org.uk>, or write to Jubilee Sailing Trust, 12 Hazel Road, Woolston, Southampton, SO19 7GA, United Kingdom.

1-8 September

Adelaide to Melbourne
8 days, \$1,746

13-22 September

Melbourne to Hobart
10 days, \$2,038

24 Sept – 4 Oct

Hobart to Sydney
11 days, \$2,257

8-27 October

Tall ships race, Sydney
20 days, \$4,538

27 Oct-5 November

Auckland to Wellington
10 days, \$2,114

8-17 November

Wellington to Nelson
10 days, \$2,114

18-27 November

Nelson to Auckland,
explore Marlborough
Sound, 10 days, \$2,114

28 Nov – 6 December

Auckland return, around
the coast of North Island
9 days, \$1,962

15 Dec – 12 February

Auckland to Ushuaia,
Argentina
\$7,225



Your Polio Support Groups

By Gary and Barbara Fuller, Support Group Liaison Officers

One of the perks of being a member of Polio NSW is that you are eligible to join one or two, or more if you like, of the twenty-two Polio Support Groups that have been established around New South Wales – and **it is free**.

One of our groups, The Hunter Polio Support Group, which meets at Toronto, celebrated its 21st Birthday on the 4th September 2013.

Members of the Polio Support Groups have a good couple of social hours, generally once a month, with people who have had a like life experience, they join together to have a talk on what they have been doing lately and tend to help each other. You are not expected to attend each meeting. If you miss one or two or even ten meetings you are just as welcome when they see you again, as if you had attended each and every meeting.

Each Polio Support Group is run by a Convenor; you have to have someone to sit at the top of the table and record the meeting attendance record and organise the regular meetings places, and sometimes the Convenor is assisted by a deputy – that is generally all there is to it. The format is usually a relaxed and informal meeting.

At the moment we need a Convenor for the Dubbo Polio Support Group and more urgently the Nepean Polio Support Group (Penrith). So do we have a member of Polio NSW out there who could fill either of these positions? Remembering that you will have the support of the Committee of Polio NSW, the Polio NSW staff at Parramatta, and the Polio Support Group Liaison Officers Gary and Barbara Fuller. You can get in touch with Gary and Barbara at:-

Address: 394 Woollooware Road, Burraneer NSW 2230 (*write or come and see us*)
Telephone: 02 9523 2428 (*has a good answering machine at all times*)
Email: supportgroups@polionsw.org.au

POLIO SUPPORT GROUP MEETING LOCATIONS—2013-2014

(as at 8 September 2013)

ACT

MEETS: 2:00 pm at Pearce Community Centre, Collett Street, Pearce
1st Saturday of every 2nd month, commencing February
CONVENOR: Brian Wilson 02 6255 0875

ALBURY/WODONGA

MEETS: Lunch on Sunday, at least four times a year
Commercial Club, Albury
CONVENOR: Margaret Bennie 02 6021 5568

BANKSTOWN

MEETS: *does not currently meet* ****WE NEED MEMBERS****
CONVENOR: Pam Solomon 02 9773 7679

CANTERBURY/MARRICKVILLE

MEETS: 12 noon at Canterbury-Bankstown Leagues Club
26 Bridge Street, Belmore – third Wednesday each month, Mar to Nov
CONVENOR: Maura Outterside 02 9718 5803

CENTRAL COAST

MEETS: 10 am to 12 noon at Kincumber Neighbourhood Centre
Kincumber Street, Kincumber – 1st Saturday each month
CONVENOR: Wayne Woolley 02 4342 6145

COFFS COAST

MEETS: *does not currently meet* ** WE NEED MEMBERS**
CONVENOR: Shirley Barnett 02 6651 9098

CONDOBOLIN

MEETS: *does not currently meet* ** WE NEED MEMBERS**
CONVENOR: Bill Worthington 02 6895 2870

DUBBO

MEETS: *does not currently meet* ** WE NEED MEMBERS**
CONVENOR: **WE NEED A VOLUNTEER**

GRIFFITH

MEETS: *does not currently meet* **WE NEED MEMBERS**
CONVENOR: Dawn Beaumont-Stevens 02 6963 0880

HILLS DISTRICT

MEETS: 10:30 am at West Pennant Hills Sports Club
New Line Road, West Pennant Hills – 2nd Monday each month
CONVENOR: Elizabeth Woods 02 9896 7818

HUNTER AREA

MEETS: 10:30 am at Toronto Workers Club, James Street, Toronto
1ST Wednesday each month, commencing February
CONVENOR: Wendy Chaff 02 4957 5254

INNER WEST

MEETS: 11:30 am to 3:30 pm at 29 Halley Street, Five Dock
2nd Saturday each month
CONVENOR: Claire Dawson 02 9713 6565

METROPOLITAN EVENING

MEETS: 6:00 pm at Canterbury-Bankstown Leagues Club
26 Bridge Street, Belmore, first Tuesday each month (Mar-Nov)
CONVENOR: Maura Outterside 02 9718 5803

NEPEAN

MEETS: *does not currently meet* **WE NEED MEMBERS**
CONVENOR: **WE NEED A VOLUNTEER**

NORTHERN BEACHES

MEETS: 10:30 am at Dee Why RSL Club
last Thursday every month, except December
CONVENOR: Pat Featherstone 02 9970 7790

NORTHERN RIVERS

MEETS: Ballina RSL in March
Lismore Workers Club in June, September and December
1:30 pm to 3:00 pm on last Saturday of the month, except December
CONVENOR: Rosalie Kennedy 02 6687 9640 0412 827 926

NYNGAN

MEETS: *does not currently meet* ****WE NEED MEMBERS****
CONVENOR: Ruth Williamson 02 6832 1220

PORT MACQUARIE

MEETS: 10:30 am to 12:00 at 9 Rivergum Drive, Port Macquarie
1ST Saturday of every 2ND month, commencing February
CONVENOR: Gail Hassall 02 6581 4759

SHOALHAVEN

MEETS: 2:00 pm at Nowra Library Meeting Room, Berry Street, Nowra
3RD Friday every month
CONVENOR: Dorothy Schunmann 0407 521 979

SUTHERLAND

MEETS: 2:00 pm at Tradies Club, Kingsway, Gympie
1ST Wednesday every month except January
CONVENOR: Ruth Hatton 02 9525 3987

WAGGA WAGGA

MEETS: 11:00 am at Senior Citizens Rooms, Tarcutta Street, Wagga
2ND Wednesday February, April, June, August, October, December
CONVENOR: Isabel Thompson 02 6926 2459

WOLLONGONG

MEETS: 12 noon at Illawarra Yacht Club, Northcliffe Drive, Warrawong
2ND Friday every 2ND month, commencing February
CONVENOR: Dorothy Robinson 02 4229 6221

There are also five Regional Representatives who give local assistance, situated in:

ARMIDALE	BLAYNEY/COWRA	MUDGE	ORANGE/BATHURST	URALLA
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Not everyone lives close enough to these twenty-two established Polio Support Group locations, so if you are interested in establishing a **new** Polio Support Group in your suburb, town or city please get in touch with Gary and Barbara Fuller and we can see just what is possible, **we can only try**. You are also welcome to get in touch with any Group to arrange a visit whilst on your travels around NSW.

So get to and enjoy a few hours with some fellow members of Polio NSW at one of these Polio Support Groups. Gary and Barbara Fuller guarantee you will enjoy these little interludes from your daily grind, as much as they do.

Seminar Report - AGM 8th December 2012

By Susan Ellis, Seminar Co-ordinator

It has taken a great deal of time and effort to finally be able to provide you with this report. Gillian Thomas has spent many, many hours editing the video, recorded on the day by Peter Garde, and has successfully uploaded it onto our Polio NSW website. The following is only part of Dr Nolan's first presentation and the remainder, which covers the ageing process and falls, will appear in a following newsletter along with his second session titled, "Cough, Spit and Breathlessness".

Dr. Nolan is a General Physician at Toowoomba Hospital, Queensland, as well as a Clinical Associate Professor of Medicine at the Rural Clinical School, University of Queensland. He has been working with polio survivors for a number of years and has a particular interest in respiratory problems in the post-polio community.

The video of Dr Nolan's talks, together with copies of his slides, are now available online on the Polio NSW website. Visit <www.polionsw.org.au/seminar/nolan> to access the material.

Post-Polio Syndrome – An Orphan Disease



Dr Nolan claims that he is not an expert in anything in particular and his involvement with polio is something that has come about through a series of events that occurred when he was training in Western Australia where he had the good fortune of working with some people involved in breathlessness evaluation who worked with the polio network in Western Australia.

Toowoomba Hospital has a medical school and has a program called The Community Partners Program. People with chronic illness or disability come in to help the students learn about their disease, for example, polio, and the students get to examine these patients.

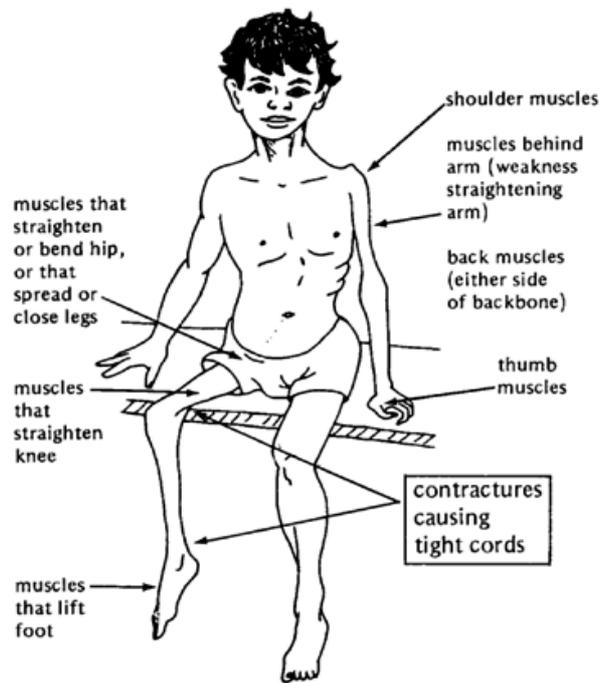
Polio has been around for 3,000 years, there is evidence in Babylonian records stating withered limbs occurring after being struck down virtually overnight.

It is a virus that causes the disease. At the time that we would have been infected 90-95% of our peers would have also been infected but with only asymptomatic or mild flu-like symptoms. The virus is purely a human virus not transmitted from other species, taken through the mouth as an enteric illness and then spreads to the nervous system where there appear to be specific receptors for the viral sheath or wall which then process it into the nervous tissue. Why would it be that only 1-2% of people who got infected actually developed the disease? We understand now that we have a genetic system in our body which influences how we respond to disease; it was your particular genetic makeup that increased your susceptibility to this type of response from the virus.

Dr Nolan has performed a post mortem on a polio patient who died of respiratory disease. He found that the focus of the disease is in the anterior motor horn of the spinal cord affecting the anterior motor horn cells that provide stimulus and supply the nerves. The nerve cells were either diseased or dead which resulted in causing muscle weakness.

Dr Nolan first met up with polio as a medical student when he found that one of his fellow medical students had had polio and experienced hand and spinal problems.

MUSCLES COMMONLY WEAKENED BY POLIO

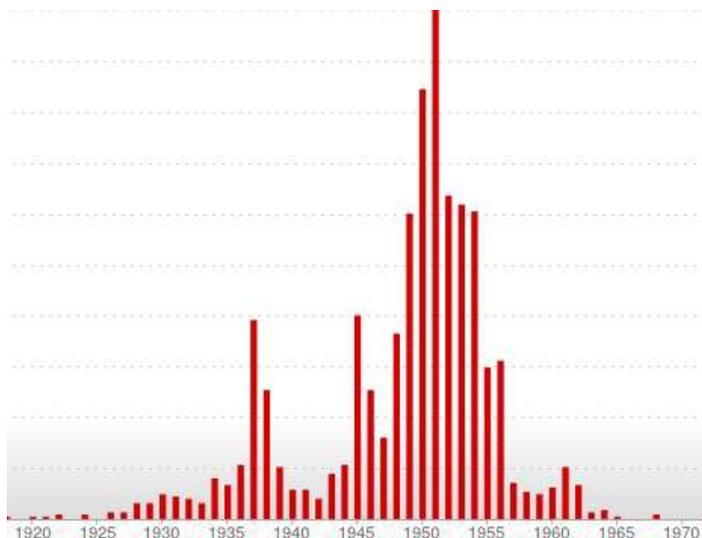


The disease can affect multiple levels in very characteristic presentations (as above) but also the mid brain, cerebrum and thalamus can be affected contrary to what some modern practitioners would say; and this probably explains a lot of things that remain poorly explained such as difficulties with blood pressure and maintenance of temperature and other issues which are clearly not to do with musculature control but are more to do with autonomic processing issues within the body.



Elizabeth Kenny came from a village south of Toowoomba in Nobby and practised in a clinic at St Vincent's Hospital in Toowoomba. She had the foresight to see that the old approach by the orthopaedic surgeons of just plastering and immobilising was not going to get the maximum function and that early mobility and stretching using hot and cold compresses was going to lead to a better outcome and a functional recovery. There is a little message there, that we might have to relearn and rethink, that immobilising a polio limb is not always the best thing to do. And similarly immobilising our entire body as we age is not always the best thing to do. *"If you don't use it you lose it"* is still important today, but remember, everything in moderation.

Dr Nolan next met up with polio survivors when he went to Western Australia where he met a polio patient who was in a ventilator and still being looked after by the same doctor after 35 years. The problem of ventilation was a big issue in acute and subacute polio and most hospitals had large centres for negative pressure ventilation and this was the advent of intensive care. It was polio that led to the development of artificial ventilation and subsequently the whole development and expansion of the specialty of intensive care.



Historic Incidence of acute polio in Australia

Polio was an endemic disease (during 1930-40s), then post war in epidemic proportions, then with a combination of things including changes in general social hygiene at the time but also the vaccination programs, it eventually disappeared during 1960s.

Dr Nolan did see two cases of acute poliomyelitis whilst working overseas in South East Asia but none in Australia's post-vaccination era.

With a dearth of accurate records of the number of people who contracted polio in Australia, the chart above is drawn from data now being collected by the Australian Polio Register (visit <www.polioaustralia.org.au> for more information).

Post-Polio Syndrome an Orphan Disease

Once our experience with the disease was initially dealt with we were immersed back into normal family life and then went through a process of normalisation. In this day and age if you were exposed to something bad you would have been seen by a therapist who would have debriefed you, supported you and helped you in your re-immersion. But that didn't happen in your era, you just had the disease and then you went home!

The mean period of hospitalisation was 26 months – for some it was 2-4 years, or 2 or 3 or 4 weeks. A lot had to depend on the resources of the family, medical staff, hospital resources, where you lived etc.

Many outside of the family never knew that you had had polio, sometimes they didn't want anyone to know out of embarrassment; sometimes it was just that they wanted to re-assimilate you back into life. Then the disease disappeared and the community forgot about it really quickly. Medical science, except for epidemiologists and public health physicians, virtually forgot about the disease.

So a lot of what polio survivors did was of incredible courage and stamina. For most of us, we just soldiered on.

Dr Nolan met another polio survivor in Perth who had a useless right arm with no function at all; she worked full-time as a jeweller's assistant for 30 years and her employer never knew that she couldn't use her right arm. Dr Nolan thought that many in the room could tell him many more such magnificent stories.

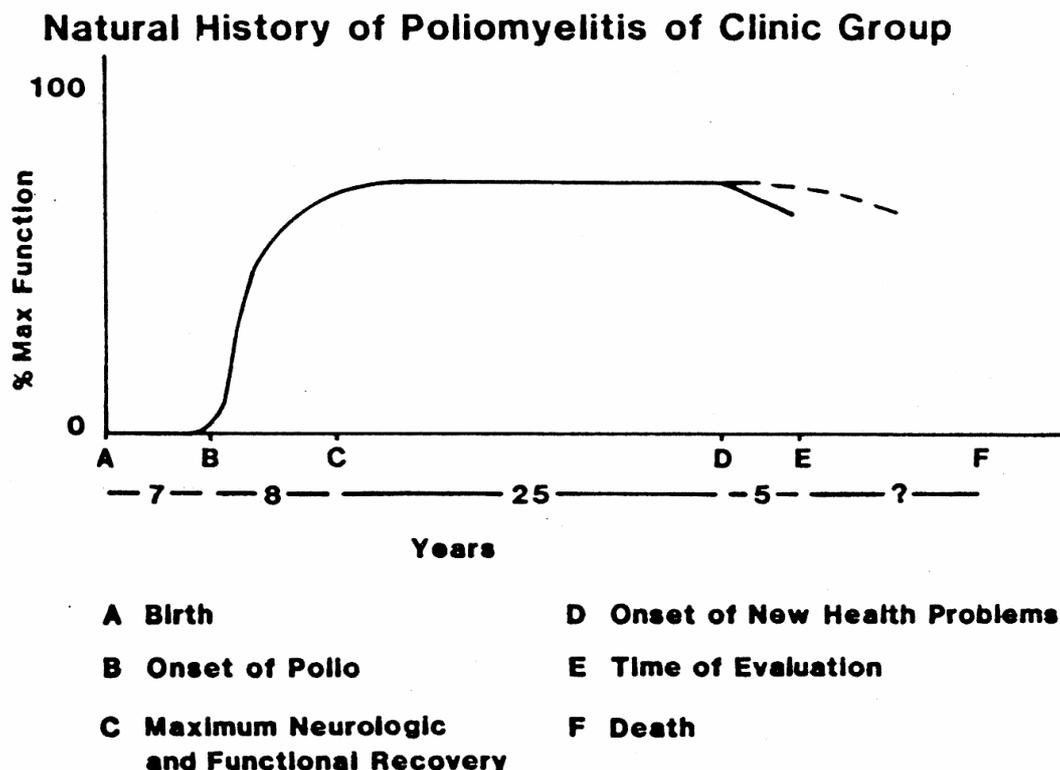
Why is Post-Polio an orphan disease?

It has no other next of kin, there is no one else out there who is similar, it is a very unique disease, and there is no other disease that causes polio apart from polio. Secondly, the memory has virtually disappeared, so the medical practitioners who were aware of this acute illness are now passed on. The medical profession has been somewhat challenged and many have pooh-poohed the whole process and have said “*well I don't think it exists, that it can't exist because it's not in my books, I didn't hear or learn about it so it can't be*”.

As a result of that there is this process of being dispossessed by the health care system and it is something that polio survivors have been fully aware of and have been campaigning for actively and still have an ongoing process to address.

So many who did suffer from polio are no longer here now though there are still well over 3,000 people throughout Australia that are actively involved in polio support groups; we know that a lot have passed away, some from preventable causes.

We do know, from an article published in a neurological book in 1957, that in 1950s centres were seeing people with late effects problems, for example, PPS, pharyngeal problems (swallowing problems) as well as upper airway function during sleep.



It took some time before it was recognised that there was a latency period between the onset of disease, the maximum neurological recovery and then later senescence, a process of change as we age. There is very strong evidence to show that the majority of people with previous polio show changes in their muscular systems earlier and at a greater rate than aged matched controls.

In aged care medicine, there is a term called homeostenosis, we get narrowed in as we age, we get corralled, it's both a physical and social phenomena that is real, that we find ourselves less capable and our social environment starts to restrict us, for example, issues of public transport, of getting into public buildings etc.

In order to include the Q&A session in this issue, and due to space constraints, the remainder of this first presentation will appear in our next newsletter. I did however want to include Dr Nolan's medical evaluation list which follows here. It is typical of his patients' yearly one-hour assessment.

A typical evaluation consisted of seven components:

1. a detailed medical history with special attention to current health problems as well as the extent of initial involvement from polio, the period of recovery, the duration of neurologic and functional stability, and the time of onset of new health problems;
2. a physical exam with special emphasis on assessing the musculoskeletal and nervous systems;
3. an electromyogram (EMG) and nerve conduction study of selected muscles and nerves;
4. a biomechanical and functional evaluation with special attention to orthotic and adaptive equipment needs;
5. a basic panel of screening laboratory tests that were supplemented with additional x-rays and laboratory studies as indicated by the history and physical examination;
6. a psychosocial assessment; and
7. referral to other members of the rehabilitation team or other medical specialists as needed.

Q&A Session:

“During your talk in reference to Sister Kenny you mentioned “If you don't use it you lose it”. What is your general philosophy on that topic?”

THE PROBLEM OF EXERCISE When, Where, How, Why?

We know from work in other areas of disability such as advanced osteoporosis that physical activity is of proven benefit and can be modified to people who can't use a treadmill, bicycle or swimming in a pool; and so doing chair exercises as a maintenance process can be designed at an individual level to help with the prevention of osteoporosis and there is a close interaction there with maintenance of muscle function.

Exercise Physiology in Post-Polio

Polio patients have a reduced exercise capacity.

- Lower anaerobic threshold (<40%). This means that the point at which your muscles start to make acid occurs much earlier, so an average sedentary person over the age of 60 starts to make acid when they get to 40% of their maximum work load, with polios that occurs at about 20% of maximum workload. That often is a factor leading to the post-exercise fatigue phenomena and the post-exercise pain phenomena. So that has to be understood when designing an exercise program.
- Low VO₂ Max (<80% predicted). We know that polio survivors' ability for their muscles to take up oxygen (VO₂ max) is diminished.
- We know however it can be improved and that exercise capacity measured as oxygen uptake can be increased by at least 20% by a 10-12 week gentle program of retraining conditioning. (Jones et al JAMA 1989;261:3255-8)

- To achieve even this 80% level of activity the average polio survivor uses excessive ventilation because that is how we get rid of the acid, we blow it off; the acid is converted to carbonic acid and we get rid of it by blowing off the carbon dioxide. So what drives a lot of our excessive ventilation during exercise is the removal of acid from the body.

Rehabilitation (in terms of exercise) in Post-Polio

GOALS:

- Restorative: Can we improve
- Preventative: Can we prevent decline
- Maintenance: If we can restore function can we then maintain it, can we try and hold that level of function as long as we can, understanding that all of us do fade with age. It is going to happen we can't stop that but what we want to do is maintain quality of life and function for as long as possible. We can't do the impossible.
- Individual specific exercises with intermittent review.

Specific exercise strategies

- Diaphragmatic breathing exercises: There are ways we can retrain breathing, even if your diaphragm wasn't involved with polio in the first instance the breathing pattern of polio survivors is often impaired and they can be taught to enhance their breathing by using a different breathing mechanism.
- Relaxation exercises for fibromyalgia: For people with pain, particularly with post exercise pain, there needs to be a wind-down process just as much as a wind-up process to prevent the development of a lot of myalgic pain.
- Soft tissue mobilisation and stretching: We also need to utilise a lot of physiotherapy technique which overlap to chiropractory etc and that is mobilisation and stretching because we generally are using things differently and often they are being overworked. The limb would become functional if there were anything more than 10% of neurons left, that a limb can get some function back even with just 10% of neurons left behind, but surely using that limb for 20-30 years is going to have some delayed impact and we think that this is part of the whole genesis of the post-polio sequelae. Those areas affected but with still more than 10% of neurons will fade with age more than a normal anterior neuron.
- Isometric exercise held for 6 seconds and rested for 6 seconds with 6 repetitions.
- Isotonic exercise with small weights.
- Aerobic exercise conditioning building up to 15 mins at 50% VO2 max 3 times/week.

Use a variety of all 3 types of exercises, must be personalised, structured and you must have rest days. Do not go all out for an hour every day; that can lead to disasters. So look at a program of no more than 3 days per week building up to 30-35 minutes per day, 15-20 minutes warm up and 15-20 minutes warm down on those 3 days. It has to be individualised. There is no generic recipe for exercise.

Chronic Fatigue

This is NOT weakness, this is fatigue. Dr Nolan was involved with a survey of 330 Western Australian polio patients and found 75% of polio survivors report fatigue (*our Secretary, Merle Thompson, reported the figure in the Polio NSW survey was 80%*). Fatigue is very disabling but cannot always be explained. Dr Nolan does not know the causes of chronic fatigue but says that chronic fatigue is generally defined as fatigue that:

- is persistent for more than 6 months,
- is of new or definite onset, (didn't exist before),
- is not substantially alleviated by rest, and
- results in substantial reduction in previous levels of occupational, social, educational or personal activities.

There is a research process with COQ10 happening at the moment, one of the specific outcomes is for it to alleviate fatigue. Fatigue appears to happen at a subcellular level, as if the cells go on a holiday. Dr Nolan said he couldn't provide any clear answers. So his approach to the management of chronic fatigue is to try and look at other subgroups of symptoms (listed below) and see if there is any management strategy for those.

Patient specific goal setting

- Improving activities of daily living.
- Vocational rehabilitation.
- Improving strength and mobility.
- Increasing exercise tolerance.
- Relieving pain. This might have an impact on the symptom of fatigue and is worth treating.
- Management of anxiety and depression. This also might be worth treating; I am not saying that it is the cause of fatigue but that it might help in the overall management of the symptom of fatigue.
- Maintenance of cognitive function.

“Why are medical specialists reluctant to advise on any treatments outside their field that might be very useful for polio survivors, for example, osteopaths, hydrotherapy?”

Unfortunately, medicine is becoming increasingly compartmentalised and the different compartments often don't talk to each other that well. Orthopaedic surgeons are increasingly fitting into that category. There are too few doctors who are too busy; hopefully with more doctors and a better balance they will have more time to listen. Hopefully, we will see more resources in the areas of rehabilitation, aged care and pain management.

There is a problem at an education level; in medical school there is no teaching on allied health or alternative therapy strategies, for example, acupuncture, hydrotherapy. The problem is that students are not well informed. Dr Nolan agreed it is amazing the outcomes that can be achieved from non-surgical therapies.

The best health outcome is when the practitioner and the patient work together as partners. The problem is finding the person who is willing to be the partner with you from the health care profession. For those patients that Dr Nolan sees with chronic illness like polio, at the end of each year he gives them a piece of paper called the *Shared Care Partnership Action Plan*. He tells them that at their next consultation to bring this back to him stating what they are going to do for their care in the next 12 months and he tells them what role he can take in this process. This is empowering the patient to be part of the process. He listens to what they are saying, because in the Plan he asks them to tell him what their concerns are and to prioritise them. Some of their issues he might not have even asked about, for example, issues of sexuality or incontinence. These are sometimes issues that are real but are not on the medical problem list and doctors tend to overlook their impact but they have just as powerful an impact as the difficulty of walking up to the shops. The medical profession needs better education and you can help facilitate this role, for example, with partnerships with Medicare Locals which will run the education programs for GPs.



We have received the following email from David Corby who is seeking information about his late brother Robert from Cootamundra. Can anyone help with David's enquiry?

I wonder if you might be able to help me.

I had a brother who was born in 1944 and died in 1959. I have always assumed that Robert had polio. Some of my relatives have the same view but others don't. Unfortunately both my parents have long gone and Robert's situation was never discussed. I was almost 8 years old when Robert passed away ... so quite young.

A cousin, who would have been quite close to our family when Robert was born, said that my Mother had a very difficult childbirth with Robert and his physical condition was caused by that. Robert died in an ambulance, at Gunning, being transported from Cootamundra (home town) to Sydney. His death certificate says that the cause of death was: "Cerebral Birth Injury" ... so maybe not polio?

Robert did attend Royal Alexandra Hospital at Collaroy in 1948 ... see attached photo. From "Polio Particles 13" by Mary Westbrook it mentions that Collaroy was used for polio patients.

I have also attached a couple of other photos of Robert ... one with myself. I do recall Robert "wearing" calipers on his legs.

Do you have any thoughts as to whether or not he might have had polio? Maybe this is a question that I will never know the answer to.

Many thanks

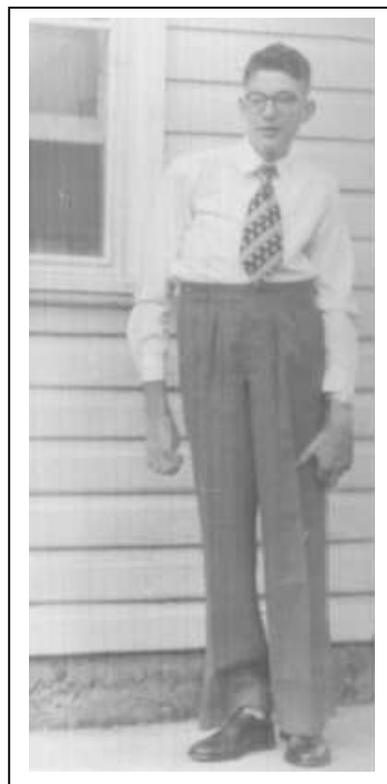
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Mobile: 0428 260 517



David and Robert Corby



Robert Corby at Collaroy



Robert Corby



2013-2014 Polio NSW Upcoming Events

Saturday 30 November AGM: 11 am Seminar: 1 pm	Burwood RSL Club 96 Shaftesbury Road Burwood	Annual General Meeting and Seminar Seminar Presenter: Anne Reddacliff The Black Dog Institute Seminar Topic: Breaking Down Depression and Building Resilience
Thursday 8 to Sunday 11 May 2014	St Joseph's Baulkham Hills Centre for Reflective Living	Polio NSW will host Polio Australia's 2014 Polio Health and Wellness Retreat <i>Email <office@polioaustralia.org.au> to submit an expression of interest to attend</i>

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Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	---
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	

Have You Included Your Polio Details on the 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. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <www.polioaustralia.org.au>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.