

POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – **Polio Oz News**

Editors: Nola Buck and Susan Ellis
Email: editor@polionsw.org.au
Website: www.polionsw.org.au

PO Box 2799, North Parramatta
NSW AUSTRALIA 1750
Phone No: (02) 9890 0946

Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

The year is rapidly drawing to a close but it isn't yet time to wind down our activities. Our 27th Annual General Meeting will be held on 5 December and you are encouraged to come if at all possible. The AGM is your opportunity to have a say in the direction and programs of Polio NSW, and to help your fellow polio survivors by standing for election to the Management Committee. The 2014/2015 reports are included in this mail out.

Walk With Me – September/October 2015

This year Polio NSW members participated with Polio Australia in two fund-raising Walks – Parramatta and Canberra. In Parramatta, Gillian Thomas and Merle Thompson raised almost \$2,000; while in Canberra, John Tierney raised over \$6,000 (*these amounts being shared between the two organisations*). These wonderful efforts not only brought in vital funds, but once again raised our profile by reminding Australia that “We’re Still Here!”. Pictured below in Parliament House are some members of John Tierney’s team – John has asked me to record his thanks to Convener, Brian Wilson, and members of the ACT Support Group, who walked with us. Member Lyn Lillecrapp even travelled from Adelaide to join in!



AGM and Seminar – 11 am to 3 pm, Saturday 5 December 2015 – Burwood RSL Club

This is a final reminder to come along to our Annual General Meeting and Seminar, *The New Assessment Clinic for Polio Survivors at Mt Wilga*. Dr Helen Mackie (Consultant in Rehabilitation Medicine and Director of the Clinic) and Nadege van Drempt (Occupational Therapist) will tell us about the Clinic and the services provided. Don't miss the opportunity to learn about how you can get your post-polio problems assessed and a management plan put in place. Ring the Polio NSW office to register (cost \$10 includes a light lunch) and also ask about your eligibility for a fuel card to assist with transport costs. We look forward to seeing you there.

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Bushfire planning leaves behind people with disabilities

by **Sarina Kilham**, Research Fellow, Centre for Disability Research and Policy, University of Sydney
Sarina Kilham is a research fellow on a project funded by Australian Aid on "Promoting the Inclusion of People with Disability in Disaster Management in Indonesia"

Reprinted with permission from "Post Polio Views", Post Polio Victoria, January 2014

When bushfires start, no one should be more worried than people with disabilities. Recent research shows people with disabilities are twice as likely to die or be injured than the general population during a disaster. They are also less likely to receive aid and less likely to recover in the long-term.

Jo Ragen, a senior research associate at the University of Sydney, describes her experience of a bushfire evacuation in the 1994 fires along Australia's eastern seaboard:

We had over 100 young people with physical disabilities at a recreational camp, and I told the [State Emergency Service] we can't be leaving on trucks. Even though they thought we had enough time to get out, in the end, that's what happened: young people were loaded onto the back of trucks and utes and we left behind what was really essential equipment for those being evacuated – wheelchairs, ventilators.

It taught me that people with disabilities need to be involved right from the planning stage. Thinking that someone is going to turn up and 'rescue' a person with a disability means someone is going to be forgotten and a catastrophic outcome is real.

As Australian authorities urge the general community to prepare and plan for bushfires, the early warning systems and public awareness campaigns are often failing to consider the needs of persons with disabilities.

Advice on the ground specifically for people with disabilities is pretty slim, and for bushfires is centred on the message of "leave early". But recent research by the Bushfire Collaborative Research Centre finds many people instead choose the "wait and see" option. In fact, less than 1% would leave their house on days of extreme or catastrophic fire danger.

This may be compounded for a person with a disability, as leaving early can be difficult as it means leaving behind essential equipment at home that is needed for daily living.

How we could be better prepared

For people with disabilities, significant gaps exist in current approaches to bushfire risk reduction.

Communications about bushfire preparedness are often not in accessible formats. There are assumptions that people with disabilities are living in households dependent on others, when many are either living independently or are heads of households.

As Jo Ragen says:

Plans that lump all people with disabilities together are like plans that say 'all people with blond hair must do this in a bushfire'. In my experience, when you wait for others to plan, or think someone else will evacuate you, you'll either get evacuated in a way that is not safe or appropriate, or you'll get left behind.

There are various measures being done to improve this situation in Australia.

For example, a recent report on "*Increasing the Resilience of the Deaf Community in NSW to natural hazards*" found that while none of the natural hazard preparedness programs or tools cater specifically to deaf people, there were communication tools that could be considered "deaf-friendly" or required only small alterations.

A recent United Nations survey consulted nearly 6,000 people with disabilities in 126 countries, and found a high proportion of people with disabilities die or suffer injuries during disasters because they are rarely consulted about their needs, and governments lack adequate measures to address them.

In cases where they need to evacuate – such as during floods or earthquakes – only 20% of respondents said they could evacuate immediately without difficulty, 6% said they would not be able to evacuate at all, and the remainder said they would be able to evacuate with a degree of difficulty.

So where does that leave Australians during what is proving to be another dangerous bushfire season?

The only way we will ensure that no one is left behind is if people with disabilities are actively included in the consultation, planning and preparedness stages of thinking about disasters. Specific input and ideas from people with disabilities is essential for identifying risks and increasing the chance of survival if disaster does strike.



Seminar Report - Retirement Living Choices for People with a Disability

by Sue Ellis

Wednesday, 3rd June 2015

Marcus Brown works for NSW Fair Trading and stood in for Alyson Dyer who was unable to be with us. Marcus is experienced with the legislation relevant to retirement village living and provides education about retirement village living across NSW. He addressed issues related to the rights and obligations of prospective residents of retirement villages. The information he provided encouraged people to make the right choice by seeking expert advice at the outset.

Moving into a Retirement Village

NSW Fair Trading provides advice when considering moving into a retirement village. There is a brochure on this subject which covers all the key issues and which can be downloaded from their website <www.fairtrading.nsw.gov.au>, or phone 13 32 20.

Marcus wanted to relay two key messages: firstly, that with retirement village living you are entering into a contract; and secondly, you are entering into a lifestyle change not just somewhere to live – it is not an investment choice, it is a lifestyle choice. To enter into a retirement village, you must be fully retired or over 55.

The contract covers the commencement of your journey into a retirement village, whilst you are there, and when you leave. Legislation contains the rights and obligations of residents and operators of retirement villages. Retirement villages must initially provide a General Inquiry Document and then a Disclosure Statement at least 14 days prior to signing a contract. When considering entering into a retirement village you can ask for these documents from the operator. It is advisable to get a number of these from different villages to compare the various facilities on offer e.g. bowling green, pool, bus service. A Disclosure Statement has more details than the General Inquiry Document and includes financial arrangements such as entry costs, live-in costs (monthly fee), and exit costs.

Contracts are required to include a cooling-off period, ingoing contribution, ongoing charges (monthly fee which changes yearly), list of service and facilities available, list of fixture and fittings provided, dispute resolution, contract termination, and departure fees.

Once you have decided what facilities are right for you, it is essential that you get legal advice to assist you to understand what your rights and obligations are. After signing a contract there is a 7-day cooling-off period. You can terminate the contract up to a 90-day settling period.

Any alterations or modifications to a property must be requested in writing, and a response received in writing, in order to get permission. These changes may have to be removed at your expense before reselling. Check before signing a contract that the premises meet your specific needs now and in the future (e.g. ramps, rails) and, if not, will they allow these alterations, or is it a problem?

It is the operator's obligation to set the monthly fees in consultation with the Residents' Committee. An audited budget needs to be presented 60 days prior to the end of the financial year.

Prospective Resident's Checklist

Marcus emphasised most importantly – **DO NOT RUSH**. Discuss your decision with family, friends and advisers. Inspect a number of villages in the area you wish to live in. Ask a lot of questions. Make sure you fully understand the contract and seek professional legal and financial advice before signing anything.

A few questions to ask yourself:

- Have I fully discussed my decision to move with my family, friends, or advisers?
- Have I thought about whether community living in a village is right for me?
- Have I looked at a sufficient number of villages to be able to compare the services, facilities and financial arrangements?
- Have I received a General Inquiry Document and Disclosure Statement?
- How much will it cost me to move to, and live in, a retirement village?
- Can I afford to live there comfortably, even when the recurrent charges rise? (At what rate do the recurrent charges go up, it is tied to the CPI, what do the charges cover?)
- Is it more appropriate that I live in self-contained (independent living) or serviced premises?
- What type of arrangement does the village offer? Is it a loan/licence, leasehold, strata, rental, or company title? Does it have assisted care and/or nursing home facilities?
- Do I fully understand the contract and all the costs involved?
- What if I decide to leave the village? Will I be able to re-sell the unit? What are the termination fees (exit fees) and charges i.e. what percentage does the operator take of the sale price and who receives any capital gain?
- How many vacant units are there in the village? (This could indicate fewer facilities and a difficulty to sell.)
- What is the average time for the re-sale or re-letting of the type of property I am interested in?
- Are the services and facilities at the village what I need? Will this still be the case as I get older or if I get sick?
- Is there adequate parking for visitors?
- Are there local facilities such as doctors, shops, hospitals, libraries, churches, clubs and public transport near the village?
- Are there village rules that may affect my lifestyle? Are pets allowed?
- Will I be able to make changes to the inside of the premises, or to have someone visit or live with me?
- Am I able to do my own gardening?
- Is the village well maintained?
- Is the village reasonably secure? Is there adequate external lighting?
- Is there an emergency call system and/or staff on call?
- Are the paths designed for easy access?
- Will my premises still be suitable if my needs and abilities change in the future, e.g. are there any stairs I will need to manage?
- Have internal modifications related to frailty, such as bath rails, been made to the premises?
- Is there a Residents' Committee to liaise between residents and the operator?
- Have I obtained adequate legal and financial advice?

Pat and Frank Featherstone have lived in their retirement village for 10 years and Pat stated that it is so important to consider your needs in, say, 10 years' time – it may be that the 'frills and fancies' of a particular retirement village (resembling resort living) becomes less important to, say, public transport, being close to shops, or if the facilities are scooter friendly.

Elizabeth and Gary Hancock have recently moved to a retirement village which is a leasehold arrangement and required no payment of stamp duty, a considerable saving. Gary commented that they took one look at their new villa and were so excited that they left a deposit that day.

Marcus stated that the operators of retirement villages are not responsible for your safety. It is important to ask what part of your medical care they can provide. What services do they provide e.g. Vital Call, 24-hour nursing? A retirement village provides independent living, assisted living is provided by hostel care, and high care is provided by a nursing home.

Marcus ended by saying that Fair Trading services are free. They provide advice, but no recommendations. They are available to give talks on various subjects to groups on request.



Robyn Helm is the Care Development Manager, Home Services, BaptistCare, Baulkham Hills. She has worked in the aged and community service area for 20 years and is committed to the provision of quality home care services that meet client expectations and needs. Robyn is a Registered Nurse with a Diploma of Management. In her presentation, Robyn covered Home Care Packages (a coordinated package of services tailored to meet consumers' care needs), referred to as Consumer Directed Care, and the changes in effect from 1st July 2015.

The Changing Face of Aged Care

Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP)

There is a need for changes due to the ever increasing percentage of the population over 65. In 1901, 3% of the population was over 65; by 2010 it was 12%, and by 2040 it is predicted to be 22%. Added to this we are having fewer children resulting in fewer workers per retired persons and hence less tax money in the coffers. In 1970 Australia had 7.5 workers for every retired person, in 2010 it was 5 and by 2050 it is projected to be only 2.7 workers. A massive review of all services needed to be undertaken not only for monetary reasons but to also make it a simpler exercise to actually access these services.

In 2012 ***Living Longer Living Better*** was released by the Productivity Commissioner and promised:

- The establishment of a new Commonwealth Home Support Program to consolidate the existing National Respite for Carers Programme (NRCP), Day Therapy Centres (DTC), Assistance in Care and Housing for the Aged (ACHA) and Home and Community Care (HACC) programs.
- To undertake work to benchmark services, review service types and trial new approaches to reablement (working with, not for).
- The establishment of the *My Aged Care* website and telephone service (a one-stop shop) in conjunction with the initial development of a future new aged care gateway.
- Initiatives to support care for people with dementia (Dementia Supplement) and linking care with housing.
- A nationally standardised basic and comprehensive assessment process (National Assessment Screening Form). (You'll only need to provide your information once.)
- Full implementation of Consumer Directed Care.
- New Home Care package funding levels introduced including a low and intermediate care package. (There are now four levels of funding.)
- Initiatives released to support diversity, strengthen the health interface and improve care for dementia.

So, how do individuals pay for this?

From July 2014 the government introduced new means-testing measures for Residential and Home Care called Income Tested Fees (ITF). If you are a self-funded retiree or part-pensioner, you may be liable for an income tested fee. These fees are currently capped at \$60,000 per lifetime.

From 1 July 2015 there are two aged care programmes for people (over 65 years) who want to remain in their home receiving support:

- **Home Care Packages Programme** – to be delivered as *Consumer Directed Care* (CDC).
- **Commonwealth Home Support Programme** – comprising *National Respite Care Package* (NRCP), *Home and Community Care* (HACC), *Day Therapy Centres* (DTC), and *Assistance in Care and Housing for the Aged* (ACHA).

Home Care Packages (HCP) Programme

This programme provides a package of care that can be managed by the individual (*the money goes to the care provider but you can choose to self-manage it*) or in partnership with a care facilitator/coordinator. The funding is given to the service provider who will deduct funds for administration and care facilitation if required.

The programme is to be delivered under the Consumer Directed Care (CDC) principles of:

- Consumer choice and control
- Rights
- Respectful and balanced partnerships
- Participation
- Wellness and reablement
- Transparency

The Home Care Packages Programme (HCP) is divided into 4 levels of support:

- Level 1 gives access to \$7,821.95 per year for service provision
- Level 2 gives access to \$14,231.35 per year for service provision
- Level 3 gives access to \$31,291.45 per year for service provision
- Level 4 gives access to \$47,566.80 per year for service provision
(Level 4 is for someone with complex needs and is equivalent to nursing home level)

Packages are allocated to providers such as BaptistCare. Individuals are able to choose which provider they prefer, the only restriction being whether the organisation chosen has the level of package still available (only a certain number of each package is allocated to providers).

Consumers have managed their own lives for a long time. They should be empowered to continue to manage their own lives by having control over the aged care services and support they receive. This requires the provision of, and assistance to access, information about service options that enable a consumer to build a package that supports them to live the life they want.

Consumer Directed Care should acknowledge an older person's right (based on their assessed needs and goals) to individualised aged care services and support.

Care and services must be within the scope of the Home Care Packages Programme. Items out of scope and not included are:

- Using funding as general income, e.g. paying bills
- Purchase of food, except as part of an enteral feeding program
- Payment of fees
- Payment for items covered under Medicare
- Entertainment activities, e.g. club memberships and sporting events
- Illegal activities

The development of respectful and balanced partnerships between consumers and Home Care providers, which reflect the consumer and provider rights and responsibilities, is crucial to consumer control and empowerment. Part of creating such a partnership is to determine the level of control a consumer wants to exercise.

Consumers should have the opportunity to work with the Home Care provider in the design, implementation and monitoring of a Consumer Directed Care approach.

Consumer Directed Care packages should be offered within a restorative or reablement framework to enable the consumer to be as independent as practical, potentially reducing the need for ongoing and/or higher levels of service delivery. There must be the assumption that the older person can regain their previous level of function and independence with reablement services being offered at a time that suits/supports the individual circumstances.

Community and civic participation are important aspects of wellbeing. Consumer Directed Care in aged care should support the removal of barriers to community and civic participation for older people if they want to be involved.

Under a Consumer Directed Care package, older people have the right to use their budgets to purchase the aged care services they choose.

To make informed decisions about their care, older people need to have access to budgeting information, including the cost of services, the contents of their individualised budgets and how their package funding is spent.

Clients in receipt of a Home Care Package are expected to make a daily contribution of \$9.77 per day. If clients are self-funded retirees, there may be an Income Tested Fee (ITF) applicable (see <www.humanservices.gov.au/customer/forms/sa456>). Any ITF fees are added to the amount of money a client spends on services. ITF is capped at approx. \$10,000 / year and \$60,000 / lifetime.

Commonwealth Home Support Programme (CHSP)

This new programme enables older people living in the community to maximise their independence. It has brought together four previous programmes to make it easier to find the help that is needed:

- Commonwealth Home and Community Care (HACC) Programme
- National Respite for Carers Programme (NRCP)
- Day Therapy Centre (DTC) Programme
- Assistance with Care and Housing for the Aged (ACHA) Programme

The CHSP delivers timely, high quality, entry level support services taking into account each person's individual goals, preferences and choice, and underpinned by a strong emphasis on wellness and reablement.

CHSP also supports care relationships through providing respite care services for frail, older people which allows carers to take a break from their usual caring responsibilities.

Types of services available through CHSP:

- *Community and Home Support* – domestic assistance, personal care, transport etc.
- *Care relationships and carer support* – flexible respite, centre-based respite, overnight cottage respite.
- *Assistance with Care and Housing for the Aged* – people at risk of homelessness.
- *Service System Development* – still to be defined

How do I access support?

All new referrals go through MyAgedCare (gateway) from 1 July 2015

Phone number **1800 200 422** or website <www.myagedcare.gov.au>

- Centralised electronic client record maintained by the gateway – this enables the client's details to be recorded once only, eliminating the need to tell 'your story' multiple times.
- Assessments will be completed by the Regional Assessment Services (RAS) for Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP).
- Aged Care Assessment Teams (ACAT) will be rolled into the gateway by December 2015.
- New National Assessment Screening Form (NASF) for all clients which will follow the client over their care journey.
- Three new portals to enable easy access to information (service provider portal, consumer portal, and regional assessment portal).

Robyn noted that Enable NSW will not provide equipment for individuals who are on a Home Care Package. The Home Care Package is supposed to supply all your needs. Gillian Thomas commented that if you needed an electric wheelchair then all of a Level 1 or Level 2 package would be taken up by that purchase.

In a nutshell – from the 1st July 2015

1. My Aged Care will start the assessment process (or getting to know your needs) with general questions.
2. My Aged Care will email your referral to a Regional Assessment Service (RAS).
3. The RAS will ring you and make an appointment time for a visit where your goals and a support plan will be discussed.
4. If you require assistance and you are over 65 years, you go to the My Aged Care website or phone 1800 200 422.
5. RAS will ask if you have a preferred provider of services.
6. You might say – “Yes, I want BaptistCare”, or you may not know a provider and so your support plan will be broadcast through the portal to all providers in your area.
7. BaptistCare (or other provider in your area if you didn’t express a preference) will pick up the referral from the portal and contact you.

Frank Featherstone asked how long does all this take? Robyn stated that once you have contacted the Regional Assessment Service they have to make contact with you within 48 hours, then once the assessment is done, the provider has eight days to provide low care services and two days for high care services.

Important to know

- My Aged Care will ask for your consent at all stages of the journey.
- Only the service provider who accepts your referral sees your information – it is not seen by other service providers.
- COTA (Council on the Ageing) are supporting all the changes and have released information specifically for clients and service providers through their website: “Home Care Today”. Robyn encourages us to take a look, it is very informative and explanatory.

www.homecaretoday.org.au

Members Questions

If you are under 65 are you eligible for Home Care Packages?

People who are under 65 can get Home Care Packages if there is a need. If you are under 65 then you may be better off going through the National Disability Insurance Scheme (NDIS). However, NDIS is not available in all areas of NSW at this point and is specifically for people under 65 who have a permanent disability. Sadly, most polio survivors are over 65 and not eligible. Robyn feels that the Aged Care sector should be able to meet our needs.

For those who are carers themselves the government provides carers support centres and respite services. Carers are also eligible for packages of care and support in their own right.

For more information: ring 1800 200 422 or visit <www.myagedcare.gov.au>

Members’ Panel: Nola Buck, David Carter, Anne O’Halloran, Merle Thompson

All now reside in retirement villages. They discuss what prompted them to consider other living arrangements, how they researched the available options, and what factors they took into account when selecting their current accommodation in a retirement village.

John Tierney lead this session and emphasised the importance of making the right decision. John outlined how his parents and in-laws all left their decision-making to move too late which caused great difficulty. He himself has made poor decisions in that they built a two-storey house on a half-acre block with large trees and lots of land that needs mowing. Then they bought an apartment off a plan and it was also probably a mistake in that it only has one lift which could be a problem if it breaks down! His point being – you can make a lot of mistakes in this area.

Nola Buck spoke about the emotional aspects of moving from the family home that they loved and lived in for over 40 years, and the sentimental issues of sorting through accumulated belongings. There were many memories – from having spent the first night of their marriage there, to bringing up four children in the house, as well as plants that had come from parent's and grandparent's gardens, it was a home filled with family history. Nola pointed out that it is a wrench to move from somewhere you are so familiar with to somewhere that would not have much character by comparison.

The reason for the move had become apparent as their home had stairs at the front and back and a sloping backyard. It was no longer suitable as ageing and the late effects of polio made it difficult for Nola to cope with the access to it – it was time to find a more accessible place to live. Nola's husband John never questioned the decision.

They then had to consider what they would like. They wanted to stay in the area, find something affordable, have an area for gardening, and a feeling of space. *"I am ashamed to say that disability requirements were not a top priority, but they were there. After all, that is why we were moving."* Nola and John looked at villas in complexes, but found nothing suitable. They were crammed together and had very little green area. Then came the thought, *"why not look at retirement villages – they usually have plenty of ground around them and as we would probably eventually move into one, we might as well make the move now"*. It was the ambience of the place that was important to Nola rather than accessibility. Originally Nola didn't think it was fair to expect John to have to go to a retirement village.

Nola and John looked at quite a few retirement villages until they found 'the one' at Pendle Hill, a small complex of 44 stand-alone, independent living, leasehold villas (1 or 2 bedrooms), built in 1983. It didn't have all the glamour of the more modern villages, but it was what they liked. It is a not-for-profit retirement village run by Uniting Care with affordable monthly fees. They were very excited once they found what they wanted and sent their deposit straight away. It was in the same area, near to an accessible railway station, shopping complexes, close to a major hospital, allowed them to attend the same church and was within scooting distance of Parramatta where there is Lake Parramatta, the Parramatta River, the ferry to Circular Quay, and the Riverside Theatre, as well as the Polio NSW office where Nola volunteers. Nola pointed out how important it is to look at the facilities that are available around, not just within, the complex itself.

They took the contract to their family solicitor who clarified different clauses with the village before signing. (Nola noted that after hearing the speaker from NSW Fair Trading they perhaps should have found a solicitor experienced in retirement village contracts.)

The move was a huge undertaking and required the assistance of her four children, one who lacked sentimentality, and Nola and John had to intervene several times to save some of their treasured 'stuff'! This was both a heart-wrenching and physical exercise, but it had to be undertaken and support is needed to achieve it. It is a really difficult job!

Nola and John are reasonably happy at Pendle Hill but it will never be the same as their own family home. Nola was concerned for John adapting to his new home. They each have their separate activities as well as shared outings i.e. concerts. John has his all-important garage to tinker in. They don't have everything they would like, the garage is not close to the villa, nor are the rubbish bins, but the villa is easily negotiated in that it is fairly spacious and easily managed. The grounds are not huge but adequate, with a gardening plot in front of each villa and a swimming pool (with some visiting ducks). Without John, Nola is not sure how long she could manage, but she would hope to be eligible for services such as domestic cleaning.

The village has a Residents' Committee to which Nola belongs; she thinks it's important to be involved in the decision-making, especially regarding the budget and maintenance fees. The committee also organises social events throughout the year.

As the village is small it does not have facilities for medium or high care, however, when residents require these services there doesn't appear to be a problem. The lack of facilities doesn't overly concern Nola. Like most people, she would hope that she will not need them!

David Carter is 75 years old, has post-polio, is single, a retired barrister, has worked in Parramatta for the last 25 years, and lived in Wahroonga. About 7 years ago David decided that with his post-polio issues, the time had come to look for a retirement village. He looked at places in Waitara, Morisset He looked at many.

His concerns were to find somewhere close to Parramatta or Wahroonga. He didn't want to go too far, he wanted to be close to medical services, Westmead Hospital. He was interested in the problems of resale of units. He bought a unit at the Anglican Retirement Village at Castle Hill (previously known as Mowll Village). He absolutely loves it there and can't imagine why he looked at anywhere else and that he couldn't live in a better place. He stated that he is very optimistic, enthusiastic and biased!

This village is a big place; it is not-for-profit, 1,200 independent living residences, 900 residents, a 200-acre site in Old Northern Road, Castle Hill. It has independent retirement units and villas, residential care hostels (4), and nursing homes on the site. It provides a range of services including cafes, library, dentist, medical centres, doctors, nurses, physios and more. Also many clubs e.g. bridge, music, bowling, legacy, church, Probus, discussion clubs. Twenty-five percent of the residents are men and 75% women.

It is a very large site; it has a commercial bus service that drives through the village daily. The way the ARV organise their financial arrangements is simple and, he believes, very good. David paid \$360,000 for his 2-bedroom unit; a fixed contract. When it is time to sell, ARV keeps 30% of the original purchase price and the remainder goes to his beneficiaries. ARV keeps any capital gain. ARV pays the 70% to the estate straight away and then they refurbish and resell the unit. Maintenance fees are \$260 per fortnight for the unit and garage.

David pointed out that every retirement village is different. ARVs are all over Sydney and have different price levels, some allow pets etc. A pitfall of going into a retirement village is that you have no idea what your needs will be in the next 10 or 20 years, what you will need then.

David's Mantra: The early you go the better, don't wait until you are 90, go as early as you can and enjoy the place.

The driving force for **Anne O'Halloran** was that she wanted to make the choice of where she lived. She didn't want to leave it too late. In 2008, she started looking. She wanted to move into a retirement village that had independent living, assisted living, and high level care.

She first started to look on the internet to find places nearby. She contacted them to send her information before she started visiting them. She quickly ruled out ones that she didn't like, until she narrowed it down to three retirement villages. She then put her name down on their waiting lists – two required a \$100 holding fee (which was refundable), while the third did not.

Anne had a pet and was managing okay in her home so wasn't in a hurry to move. Over a period of time she was called to look at 6 units and eventually narrowed it down to 2 that she liked, but ended up missing out on the one she preferred.

Anne moved to Southern Cross Care at Marsfield. There are 72 units with 72 women and 12 men, some couples. There are three levels of care.

Most of the units she visited didn't really cater for residents with long-term disability. At the time she was coping and didn't think she would deteriorate any further and would be okay. Then Anne had a fall and fractured her leg which set her back and took away some of her confidence.

Anne's advice is to ask for modifications if needed i.e. her clothes line was too high; the door to the shower was removed after her rehab. Positioning of the recycling bins are a problem.

In hindsight, Anne would do some things differently. She would pay the removalist to pack for her (an extra \$700). Family members and friends did help pack but it meant that Anne also had to help them which was exhausting. It would have been better to have them help her to unpack because there is less pressure then, you can take your time.

Anne noted that there is a group that advertises in the Seniors' magazine who can do it all for you, pack, move, get rid of stuff for you: *Downsizing with Ease*, Lorraine Cox 1300 795 526
Email: <Lorraine@downsizingwithease.com.au>. Website: <www.downsizingwithease>
You can download their "10 Tips to Making Downsizing Easier" booklet.

Anne also advises that you should accept any offers of help and not try to be so independent (it all helps), take more rest breaks and accept a longer settlement so you don't have to be rushed into a short time frame of selling house, paying deposit and moving. Also, don't look at everything when you go through things, it can waste so much time.

Anne still wonders if she should have stayed put, after all she did have helpful neighbours. Did she do the right thing at the right time? However, home maintenance was becoming an issue and the house was too big. Other considerations when making her decision were that she wanted to be near relatives and friends and shopping centre that provided scooters.

Anne also commented that even though there are three levels of care at her retirement village there is no guarantee that you will be able to move into the other levels of care if there isn't an available bed.

An audience member noted that local papers often advertise Open Days at retirement villages so you can see them and speak to residents to get a feel for the place. Anne stated that some units in her retirement village were rented and others purchased.

Merle Thompson presented a slideshow which provided a summary of things to consider when making a final decision. The retirement village where Merle lives is in Lithgow and is owned by a private operator. It doesn't have any later-care facilities. The financial arrangement differs with her village in that, when you sell, the capital gain goes to the owner; the exit fee, which goes to the retirement village owner, is 30% of the purchase price (entry fee). The maintenance fee per month is \$260.

Why did she move into a retirement village? Merle had lived for 30+ years in a house with her older sister, Lyn. They had planned to move, but unfortunately Lyn passed away after a short illness. Merle's big sister/carers was determined, before she died, to find a place for Merle to live. They decided the retirement village would give Merle independence, physical help and companionship.

The retirement village would hold a deposit for 6 months until their house was sold. It was 5 months later that Merle moved in on her own.

It has a community-village feeling and is pet friendly which allowed Merle to take her cat.

Things to consider: What is the village community like, what shops and services are available and what social and cultural activities are there? How isolated or integrated is the retirement village in the wider community? If you don't drive, how accessible is the broader community?

Merle is happier in a smaller shopping centre, she doesn't like big complexes, she feels that it is friendlier and has a sense of community.

Management: Her retirement village is privately owned, had 35 villas at first and will have 148 eventually; at present there are 60 villas. Merle feels that the privately owned village has a more personal feel. It doesn't have as many facilities as perhaps David's and therefore the maintenance fees are less. There are no nursing services. The village grounds have no steps, and low gradients.

Merle's villa also has no steps; her garage is attached with an internal door into the hallway. Her clothes line is in her courtyard. There are visitors' parking spaces available.

Medical and transport: There is a bus stop, post box, and medical centre just outside her village, and a local hospital close by providing most services. The railway station is 4 kms away, it has a lift and a ramp and no gap between the train and platform.

Things to check out: needs to be wheelchair accessible – look at bench heights, bathrooms, kitchen arrangements, storage space, are hallways wide enough for a wheelchair, is the bedroom big enough for wheelchair moveability? What is the outlook like outside your windows? Look at heating and cooling issues – fans. How much freedom is there to make changes/additions inside and outside your villa? e.g. add awnings, rails, choice to do own garden or get help.

Community Facilities: There is a Lifestyle Centre which has good wheelchair access, has a meeting and activity room, lounge, library and a pool table. There is a transport bus for outings, e.g. shopping. Activities – carpet bowls, pool, darts, scrabble, mahjong, music appreciation etc.

Drawbacks: Distance from Sydney, 3 hrs in the train or 120 km by car. The village is a community: some people are pleasant, some less so, and then a few are problematic, and some things can disrupt your harmony – all are issues to consider when living in a community environment.



Reprinted from The DAISI Link – Spring 2015, newsletter for the Disability and Aged Information Service Inc

For more information:
phone **1300 650 835**
or visit <www.returnmed.com.au>

Return your unwanted medicines to your pharmacy for safe disposal. Old medicines lying around the home 'just in case' are dangerous

Most of the medicines in our medicine cabinet we need, but what about the yellow pills in a jar that's lost its label, and the eye drops we have had for a long time. And what was that Quivinox B-Sulphamate for?



If taken when they're out-of-date

If taken when not prescribed for you

If in reach of little prying fingers

The RUM Project provides the safest and easiest way to dispose of unwanted and out-of-date medicines. It makes possible the return of all household medicines to any pharmacy at any time – for free and safe collection and disposal.

Don't flush medicines down the toilet

Don't pour medicines down the sink

Don't throw medicines into the garbage bin

RUM provides the best alternative – by returning out-of-date and unwanted medicines to our local pharmacy, we can make our home a safer place, help safeguard our community, and protect our environment.

Step 1 – Sort through your medicine cabinet and drawers, putting to one side the out-of-date and unwanted medicines;

Step 2 – Take them to your local pharmacy;

Step 3 – Give them to your pharmacist for proper disposal; and

Step 4 – Tell your friends and relatives about the RUM Project.

Vale Ken Dodd

by **Nola Buck**

It was with sadness that Polio NSW learnt that member Ken Dodd had died in June. Ken was a larger-than-life person and he will be greatly missed, especially by people in the Coffs Harbour/Bellingen area. Polio NSW would like to express our sincere sympathy to his wife, Claire (also a member of Polio NSW for many years), and his daughters on their loss.

Ken contracted polio at age 2 in 1930 in Harden, NSW. He spent about 2 years in the Coast Hospital (Prince Henry Hospital) and Camperdown Children's Hospital. He experienced the usual treatment following the initial polio attack, mostly conventional but some Sister Kenny. He attended Canterbury Boys' High School and decided in 5th Year that he would like to become a teacher.

This was in 1947 when people with any kind of physical disability could not enter the Public Service. When Ken's first appointment as a teacher arrived it was only as a temporary staff member. This meant pay restrictions, no superannuation and no promotions. Ken did not accept this situation. He immediately went to the Education Department in Bridge Street, Sydney, and followed the doctor who had conducted the medical to his rooms where he and Ken carefully went through Ken's sporting activities at Teachers' College, some quite correct, some not so. After a short time, the doctor tore off the margin of his Sydney Morning Herald and wrote, "*K.R. Dodd, medically fit, N.J.*" Clutching this magnificent document in his hand, Ken proceeded to the Accounts Department and left with his superannuation papers.

Ken was very active in his community and the following are just some of those activities:

- Librarian at Bellingen RSL;
- started soccer locally, both Junior and Senior;
- zone-qualified basketball referee;
- Board member of Bellinger River District Hospital;
- active member (and Life Member) of NSW Primary Schools Sports Association;
- Teacher's Federation Representative (and Life Member), Bellingen;
- Life Member of the NSW Teacher's Federation;
- President (and Life Member) of Urunga Golf Club;
- engraving of trophies for local schools and sporting groups (and for Polio NSW);
- Probus Club Secretary for approximately 18 years, and also President;
- Life Member of the Fernmount Bushfire Brigade; and
- a volunteer in the Disadvantaged Schools Programme.

The following are some of Anne O'Halloran's memories of Ken. Anne started the Coffs Harbour Support Group, of which Ken was a keen member and later Convener.

Ken became an active member of the Coffs Harbour Support Group in 1991. We met monthly at a Community Centre in Coffs. I remember Claire accompanying Ken to meetings. Some of our Support Group members travelled from Nambucca Heads by wheelchair bus/taxi and Ken was always a willing helper for the members when they arrived in Coffs. Mike and I returned to Sydney in 1998 and one particular memory I have of Ken is the help he provided to one of our Sydney members who was leaving hostel accommodation in Sydney to be closer to her son on the North Coast. I contacted Ken who found a suitable leisure type of unit in a village near Coffs where people with a disability were catered for and he sent her information. The lady moved up there. Ken visited her in hospital when she had an accident at the new abode, providing our member with valuable support.

When I ran across Ken and Claire in Urunga they would tell me they spent many happy hours canoeing together on one or other of the rivers in the area.

I take this opportunity to express my condolences to Claire and their family. Ken will be missed, not only by his family, but in the communities of Fernmount, Bellingen and Urunga.

Promoting Positive Solutions

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Question: *I worked so hard to walk again after acute polio. I have extreme pain in my hip in my weaker leg and since I had a knee replaced my back pain when standing is also extreme. I use a cane sometimes and I know I should use a scooter or a wheelchair, but I just can't overcome that horrible feeling of being a failure if I do. Besides that, I have gained weight and if I don't move some I will gain even more. Help!*

Response from Dr Rhoda Olkin, PhD

Dr Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and a single mum of two grown children.

Ohhh, been there! I have pain in my knee area, my back hurts, I can't stand for more than a minute, and I spent my formative years doing everything possible to remain ambulatory. Now I use a wheelchair or scooter 90% of the time, crutches the remaining 10%, starting about 10 years ago. My weight gain has been alarming, and I no longer see in the mirror the person I think I am from the inside (who seems to be much younger, cuter, thinner and with great hair!). But I do not see a failure, only flaws that I can address. The flaws do not include the fact that I use a wheelchair, because doing so got me my life back. Pain and limited ambulation were forcing a reduction in activities that narrowed my world.

We get so many messages from everywhere about how walking is good and how the need for any sort of assistive devices is bad. Consider the language often used: "Wheelchair bound" (with emphasis on the inability to get out of the wheelchair), "non-ambulatory" (not able to walk), "suffers from polio" (as if that's all you are). What if we said "uses a wheelchair" and "fully mobile" (by whatever means!) instead? A wheelchair is not a failure, but a window into a wider world of options. Imagine you lived in a poor country with no access to wheelchairs. In such circumstances people devise their own sets of wheels, and getting a real wheelchair would not represent failure, but wings to fly.

Try to experiment. Go to a big store that has a scooter for customers to use. Do not use it. Go up and down each aisle. Note your level of fatigue and pain. Now go on another day and use the scooter, again going up and down each aisle, and again noting your level of fatigue and pain. What do the results tell you?

Okay, I'm not going to gloss over the significance of using a wheelchair. First, using a wheelchair often means less overall body movement, which can lead to secondary conditions (weight gain, decubitus ulcers, lassitude of some muscles). You have to be careful to avoid these. Since you can walk, do so a bit, or get on the floor and move/exercise, or do chair exercises. (Once a day I walk with crutches from my office to the bathroom and back, a total of 100 steps. I notice I feel better when I do this.) Second, it's a change in body image. People everywhere start reacting to you differently, and that feedback forces some recalibration of the self. Third, it can be harder to maintain or lose weight. Make sure you don't have another condition (hypothyroid, sleep apnea) and then find a balance in intake and output that you can live with. And when you do, write me, so I can use it as well!

Do not let anyone – family, friends, doctors, rehabilitation specialists, physical therapists – lead you to believe using a wheelchair represents failure. It is an alternate means of mobility and does not change the fundamental you.



Question: *Sixty years later I still live daily with anxiety stemming from hospital treatment, not abusive but certainly traumatic for a child. Do you have suggestions on how I can reduce the stress of this anxiety?*

Response from Stephanie T Machell, PsyD

Dr Stephanie T Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

So many of my clients struggle with this! The hospital experience was indeed traumatic. You had a serious life-threatening disease that in its acute phase included severe pain, a high fever and the inability to move and/or breathe on your own. Your family was absent and often unable to visit even briefly. And the treatments themselves could be painful and at times humiliating.

And no one was explaining why any of this was happening or letting you express your fears. If you tried, you were told to be brave, that big girls and boys don't cry, or something similar. At that time pediatric professionals believed that children didn't experience depression or anxiety and that only a disturbed child would suffer long-term emotional effects from polio.

Of course that wasn't true. And because what isn't addressed cannot heal, you like so many others still suffer the after-effects.

Anxiety can manifest as panic, worry, ruminations, obsessions, compulsions, frightening intrusive memories or nightmares, phobias, fears, a sense that something terrible might happen, avoidance of places or experiences (for example, medical care or wearing heavy clothing). Most likely you have more than one of these symptoms.

There are many self-help techniques for reducing anxiety. Mind-body techniques such as meditation, relaxation, guided imagery, gentle yoga, or tai chi "reset" an overactive autonomic nervous system.

Grounding techniques interrupt panic or flashbacks. For example: Open your eyes. Feel your feet on the floor and/or your butt in the chair. Breathe steadily. Look at something that reminds you you're safe.

Worriers can set a worry time of 15 minutes at the same time every day. For the other 23 hours and 45 minutes, when you catch yourself worrying, stop and say, "*I need to save this for worry time*". When worry time comes you MUST worry for 15 minutes. When the time is up, you MUST stop worrying until the next worry time.

Writing can be helpful. Part of what makes trauma traumatic is that it is unspoken and unshared. Putting your experience into words, even if just for yourself in a journal, helps you process and make meaning of your experiences. Others have used art in this way.

Reading about the trauma of polio helps some and overwhelms others, so use your judgement. Along with many memoirs there are some useful articles about trauma and the polio survivor. The best one, "*Bridges to Wellness*" by Linda Bieniek, is on the Post-Polio Health International website. The Lincolnshire Post-Polio Library contains some excellent articles. Though not specific to polio, there are also workbooks and self-help books for reducing anxiety and other after-effects of trauma.

Have you seen a psychotherapist? If no one in your area works specifically with polio survivors, look for someone who deals with trauma and/or disability. Many of my clients have found that once they dealt with their trauma, they had a reduction in their PPS symptoms, especially fatigue and cognitive difficulties. Finding a therapist and going through therapy isn't easy. But healing is worth it.



Dr Stephanie Machell will be a Keynote Presenter

*Resilience and resistance:
a consultation with the polio patient*

at Polio Australia's
2016 Australasia-Pacific Post-Polio Conference
Polio – Life Stage Matters



**2016 Australasia-Pacific
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Summary of Poliovirus Genome in Patients with Post-Polio Syndrome

Mid-Study Report to Post-Polio Health International (PHI)

by Joan L Headley, Executive Director, PHI

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In late 2013, Post-Polio Health International awarded \$100,000 to the team of Antonio Toniolo, MD; Andreina Baj, MD; and Martina Colombo, PhD – Laboratory of Medical Microbiology and Virology, Department of Biotechnology and Life Sciences, University of Insubria Medical Center, Varese, Italy, to expand its search for poliovirus genome in various populations. The team's work is enhanced by the expertise of Konstantine Chumakov, PhD, Associate Director of Research, Office of Vaccines Research and Review, FDA Center for Biologics Evaluation and Research, Silver Spring, Maryland.

The goals are: 1) to complete the systematic search of poliovirus genomes in the Italian cohort of post-polio syndrome cases, and 2) to verify if poliovirus genomes are also present in aging polio survivors with "stable polio" (i.e., those aged > 60 years that have not developed post-polio syndrome).

The team will compare virus prevalence of point 1 versus point 2 with the aim of establishing whether the presence of persisting polioviruses may have a pathogenic role in post-polio syndrome and of defining the peculiarities of genomic sequences of polioviruses detected in cases with post-polio syndrome as opposed to the genomic sequences of wild-type polioviruses.

Why look for poliovirus genome?

For many, the origin of post-polio syndrome is still poorly understood. Some do not question its origin, but attribute its consequences to living active lives with bodies that have fewer nerves and fewer muscles. Time and age takes its toll. But, looking for an additional explanation makes sense.

Persistent poliovirus (PV) infection has been reported in individuals with B lymphocyte deficiency (and low or absent serum immunoglobulins; Li et al, 2014). Some evidence suggests that persistent PV infection could be associated with post-polio syndrome (Leon-Monzon et al, 1995; Baj et al, 2015).

Inflammatory changes in meninges, spinal cord and muscles have been reported (Ikemoto et al, 1996; Semino-Mora & Dalakas, 1998) and may suggest: persistent PV infection, autoimmune attack to central nervous system (CNS) targets, increased vulnerability of CNS to further infections.

What has been accomplished?

Polio patients have been seen by neurologists and appropriately diagnosed with post-polio syndrome (PPS) (or other forms of polio) using current diagnostic criteria (Farbu et al, 2011). Participants in the study have included PPS cases, stable polio cases, polio-free family members of PPS patients, non-polio neurologic controls and healthy blood donors.

What are some preliminary results?

Low-level genomes and infectivity *related to any one of the three PV types* have been detected at high frequency in PPS patients decades after the acute attack.

An additional conclusion of relevance to the field of public health (and also important for family members and co-workers of PPS cases) is that PV infection if not being transmitted from PPS patients to their family members.

Since effective treatments for PPS are still missing (Koopman et al, 2011), identification of chronic PV carriers might indicate the need of treatment with human IgG or antiviral drugs/antibodies that are under development (McKinlay et al, 2015). Some treatments (human immunoglobulins) are currently under clinical trial in a multicentre international study (<post-polio.org/edu/pphnews/PPH31-3sum15p3.pdf>).

What are the team's next steps?

Select viruses isolated from PPS cases are being examined at the FDA in order to define the peculiarities of genomic sequences of polioviruses present in PPS cases versus those of wild-type polioviruses.

The recruitment of polio survivors with "stable polio" is continuing, to extend the observations from the current to at least 30-40 cases.

The team will evaluate if anti-poliovirus antibodies may be effective in blocking the infectivity of poliovirus strains derived from PPS patients.

If positive, the results of the above tests will allow the team to propose “specific serotherapy” for treating PPS. In the meantime, they want to understand the possible role of poliovirus antibodies in the current therapy that is mainly based on the infusion of human immunoglobulins.



Dr Antonio Toniolo will be a Keynote Presenter

*Post-Polio Syndrome as a viral disease:
research results*

at Polio Australia's
2016 Australasia-Pacific Post-Polio Conference
Polio – Life Stage Matters



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The NDIS will be rolled out across NSW between 1 July 2016 and 30 June 2018.

From 1 July 2016, people living in Hunter New England, Southern NSW, Central Coast, Northern Sydney, South Western Sydney, Western Sydney and Nepean Blue Mountains will be able to access the NDIS.

From 1 July 2017, the NDIS will be in place across the rest of NSW, and people living in Northern NSW, Mid North Coast, Sydney, South Eastern Sydney, Illawarra, Shoalhaven, Murrumbidgee, Western NSW and Far West NSW will be able to access the NDIS.

Information is now available on the National Disability Insurance Scheme website re the roll out of the scheme across NSW and Victoria. For more information on the rollout of the NDIS in NSW visit:

<www.ndis.gov.au/about-us/our-sites/nsw>

Companions in the Air - A Helping Hand When You Travel

*From The Senior Traveller EXTRA Tuesday, 6th October, 2015 Section:
Travel, International travel, Travel Tips*



Singapore Airlines has partnered with *Medical Travel Companions* to offer a premium service for independent travellers who need assistance when they travel.

Medical Travel Companions can help with things like checking in luggage, clearing immigration, supervising medication while in transit and providing wheelchair assistance.

Companions are fully qualified nurses or paramedics and are matched to the passenger's needs. At present the service is limited to outbound flights from Australia and fees apply.

Ring **1800-070-051** or visit **<www.singaporeair.com/mtc>**

Driving

Reprinted from the newsletter of IDEAS, Sept/Oct 2015

Driving is often a goal for everyone and that includes people with a disability or someone who is recovering from an injury or illness. It is an activity that is important in everyday life and it enables individuals to become involved with their community. It gives a person a sense of freedom and independence.

Having support by your side when you are learning how to drive for the first time or after an injury is vital. There are many of these supports around to help you get back behind the wheel.

For information about driving rehabilitation in your area please contact IDEAS on their toll free number: 1800 029 904. They will be happy to help you find a service to suit your needs.

Sydney Festival Unveils 40th Anniversary Celebrations

Reprinted from the newsletter of Spinal Cord Injuries Australia (SCIA), Accord, Spring 2015

International as well as home-grown talent will light up performance stages to celebrate the Sydney Festival's 40th anniversary in January 2016.

"The New South Wales Government is proud to support Australia's biggest and best summer festival. Over four decades, it has grown to become a wonderful showcase of home-grown and international talent", says NSW Deputy Premier and Minister for the Arts, Troy Grant.

During the three-week Festival from 7-26 January, events will be held in various indoor and outdoor locations and performance spaces. With a vast array of music, film, dance, opera, theatre and exhibitions on offer, there is definitely something for everybody.

The 2016 program is now available. *"Sydney Festival is proud to present international work by some of the world's most extraordinary artists including Peter Sellars, Toni Morrison, Rokia Traore, Robert Wilson, Tom Waits and Jette Steckel ...",* says Festival Director Lieven Bertels.

One of this year's theatre highlights is the play *Woyzeck*. *"The piece is wild and lurid and exciting and it inspires your imagination. It makes you fear for the characters and reflect on your own life",* writes musician and actor Tom Waits.

Spinal Cord Injuries Australia (SCIA) encourages all people with disability, their family and friends to attend the Festival. There are a large number of free as well as paid events around the city and Darling Harbour, and outdoor concerts in the Domain as well as around the city on Australia Day.

The Festival has a ticket pricing policy that offers people with disability the lowest priced ticket category for each event. Plus, it accepts the Companion Card. Discounts are also available when purchasing tickets for multiple events.

Although Festival venues, services and facilities should provide equitable access in compliance with the Sydney Festival Disability Action Plan, access barriers have occasionally occurred in the past. However, Festival organisers respond when issues are raised. If people have any adverse experiences, SCIA recommends raising these issues directly with the Festival organisers.

For more Sydney Festival 2016 details, visit <www.sydneyfestival.org.au>, phone (02) 8248 6500, or email <mail@sydneyfestival.org.au>.

Companion Card information is available by phoning 1800 893 044, emailing <companioncard@nds.gov.au>, or visiting <www.nswcompanioncard.org.au>.



Following are two emails received recently from members. Can you help Ann-Mason Furmage who is contemplating a shoulder replacement? There is also some mobility equipment for sale with first offer to polio members.

I have been advised that I need to have my right shoulder replaced, due to wear-and-tear during the 65 years since I had polio (my left hand-arm-shoulder is paralysed, so my right shoulder has done double work for a long time).

I am not particularly excited about the prospect of this operation, but even less enthusiastic about the fact that my shoulder would be immobilised for 6 weeks after the operation.

In addition, I am concerned about the effect of the rehabilitation exercise regime which would follow the operation.

I wonder if anyone else in Polio Land has had a shoulder replacement operation and what their experience may have been? I would be very grateful if you could share this with me.

Ann-Mason Furmage Email: <arose@exemail.com.au>



Hello Gillian

As you know, Ken Lambert passed away recently. His wife, Marion, and their son, Ian, are offering Ken's mobility equipment for sale, with first offer to polio members. If anyone is interested in anything, please contact Ian directly. His details are below.

Brian Wilson, ACT Support Group Convener

Dear Brian

I take this opportunity to thank you for your support for Dad over these recent years. With Dad's death we are now trying to sell his various items of mobility equipment. I would be pleased if you could pass around your network that the following items are available:

Mobility scooter Shoprider Deluxe 889. Complete with accessories like sun canopy, carry basket, charger etc. Good condition. It is about 5 years old and was used by Dad every other day up until the last three months. Still holds a charge and runs well – I took it for a spin myself last week. I don't know when the batteries were last changed. Price around \$1,000.

Cougar Power chair \$1,500 ono, with recent new battery pack valued at \$660. Good condition.

Dad's car is also available. The vehicle is a silver **Ford Escape 2002 BA XLT 3LT AUTO**, 140,000 km, **complete with hydraulic mini-crane and 3-wheel mobility scooter**. As a package we would be asking around \$6,200, ono. We will get a RWC for it before sale. Rego runs out mid Dec.

All prices negotiable.

I am happy to answer any questions by email or phone.

Thank you for your assistance.

Ian Lambert Email: <ianlambert@gmail.com> Mobile: 0447 965 900





2016 Polio NSW Seminar Program

Wednesday 18th May 2016	Northcott 1 Fennell Street North Parramatta	Mid-Year Seminar <i>Look for details in upcoming Network News</i>
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Management Committee – Executive Members Contact Details

Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
Susan Ellis	Vice-President	vicepres@polionsw.org.au	02 9487 3094
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
Alan Cameron	Treasurer	treasurer@polionsw.org.au	0407 404 641
Committee Members (for contact details please ring or email the Network Office): Charles Anderson, Anne Buchanan, Nola Buck, Ella Gaffney, Anne O'Halloran, Alice Smart and John Tierney			

PPN Office and Other Contact Details

Office staff: George, John and Fatma		office@polionsw.org.au	02 9890 0946
Volunteers: Nola			02 9890 0953
Anne O'Halloran	Seminar Co-ordinator	seminar@polionsw.org.au	02 8084 8855
Ella Gaffney	Website Webmaster	webmaster@polionsw.org.au	0407 407 564
	Support Group Co-ordinator	support@polionsw.org.au	
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	---
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	02 9890 0946

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.



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Polio - Life Stage Matters

**20-22
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SYDNEY**

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Visit <www.postpolioconference.org.au> for more information

About Polio NSW

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors. In 2011 the Network changed its name to Polio NSW Inc but our services for polio survivors remain unchanged.

Polio NSW is a self-help, self-funded organisation governed entirely by volunteers. Polio NSW provides information about polio's late effects and supports those who may be affected now or in the future. We conduct regular Seminars and Conferences, publish *Network News*, foster the establishment of regional Support Groups throughout NSW and the ACT, and maintain a comprehensive website.

Polio survivors, their family members and friends are all welcome to join Polio NSW, as are health professionals and anyone else who supports our aims. Membership provides information and support that can maximise the physical and psychological quality of life of polio survivors and their families.

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of Polio NSW's income, which is used to provide its services, comes from membership subscriptions and donations.

Resources for Members

On joining Polio NSW, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a *Medical Alert Card* which can be carried in the wallet.

Polio NSW also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for members and postage is included. To order, just write to us – please make cheques / money orders payable to Polio NSW Inc.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> Second Edition Edited by Lauro S Halstead MD (<i>see description below</i> 📖)	288 pages	\$40.00 <i>incl 10% GST</i>
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 <i>1st copy free</i>
Polio NSW has for sale a four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about Polio NSW. Not only is the badge a great fashion statement, it is an innovative way to promote Polio NSW.	23 mm x 23 mm	\$5.00 <i>plus \$1 postage</i>

📖 ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:

As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are “pioneers” – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Office.



Volume 5, Issue 3

Polio Oz News

September 2015—Spring Edition

Body, Mind and Soul Retreat—New Zealand Style



By Mary-ann Liethof, National Program Manager, Polio Australia

Body, Mind and Soul Retreat

Houchen House, Hamilton, New Zealand

Thursday August 06th to Sunday August 09th 2015

For the past couple of years, [Polio New Zealand](#) Board Members have been visiting Australia to check out our Retreats and to sit in on Polio Australia's 3 year Strategic Planning meeting. Well, this year, it was Dr John Tierney (President of Polio Australia) and I joining our cousins across the ditch for their first ever Health & Wellness Retreat, which they are hoping will become an annual event.

On Wednesday 5th August, John and I flew into Auckland from Sydney and Melbourne respectively, and managed to time our flights to within 10 minutes of each other. We were greeted by rain, and by the time we were able to clear Customs and collect the hire car, we were in the thick of Auckland's peak hour traffic. Who knew Auckland had so many cars?! By the time we

reached Hamilton, it was around 7.15pm and pitch black. Of course, that is 5.15pm Australian Eastern Standard Time, but the traffic and driving conditions were exhausting enough to acclimatise us instantly.

We could have booked to stay at Houchen House for the extremely reasonable cost of NZ\$45 per night per bed - 16 single rooms, and 2 twin rooms. (This was separate to the cost of the Retreat.) Call us 'soft' but we passed on this offer in favour of a hotel with ensuite bathrooms. Around 40 people have booked in to the Retreat, so all the available beds were snapped up anyway. Everybody's happy!

[Houchen Retreat House and Conference Centre](#) is set in five acres of gardens boasting native bush and lots of bird life, ten minutes' drive from the centre of Hamilton. It was promoted as being "*an ideal location to revitalize your spirit in the serenity of the spacious grounds, while enjoying the company of others who have survived polio.*"

Cont'd p4

National Patron: Dr John Tierney, Ph.D, DAm

Polio Australia

Representing polio survivors
throughout Australia

Suite 119C, 89 High Street
Kew Victoria 3101
PO Box 500
Kew East Victoria 3102
Phone: +61 3 9016 7678
E-mail: office@polioaustralia.org.au
Website: www.polioaustralia.org.au

Contacts

President—John Tierney
john@polioaustralia.org.au

Vice President—Gillian Thomas
gillian@polioaustralia.org.au

Secretary—Jenny Jones
jenny@polioaustralia.org.au

Treasurer—Brett Howard
brett@polioaustralia.org.au

National Program Manager
Mary-ann Liethof
mary-ann@polioaustralia.org.au

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From the President

*Dr John Tierney
President*

Well it is that time of year again where, in a number of state capitals, you will have the opportunity to support Polio Australia's "Walk with Me" efforts, which will again be held under the umbrella of *Ability First Australia* and sponsored by Dick Smith. Last year for the first time Perth and Adelaide joined in and this year we plan to hold our first ever "Walk with Me" in Canberra. More information about how you can participate and/or sponsor an individual or team can be found on page 7.

The growing link between Polio Australia and Polio New Zealand continued last month when Mary-ann and I headed across the ditch to take part in their first Health and Wellness Retreat in Hamilton, just south of Auckland. In recent times a number of executive members of Polio NZ have attended our Health and Wellness Retreats and joined our 2014 AGM as observers. There were about thirty participants at the Retreat and a great bond developed over the three days. As usual, we picked up some more useful information on how to manage the LEOP condition from workshop providers. Mary-ann and I were both given a guest speaking spot at the evening dinners. Mary-ann provided an update on the Australasia-Pacific Post-Polio Conference in Sydney in September, 2016, and I spoke about Polio Australia's growing links with Rotary. This includes fund raising activities, and our

recent major breakthrough with Rotary District 9685, who are funding the delivery of ten clinical practice workshops on the LEOP for health professionals in their district (more on page 12). The most inspirational session at the Retreat was a motivational speaker, Barry de Geest, who is living with the effects of the Thalidomide drug, which his mother had been taking before he was born. This left him with no arms or legs, only two feet. Yet over fifty years Barry had managed to build several successful businesses, marry, and have children. A truly amazing man.

Following my call at the Torquay Retreat in April for more Speakers for our "We're Still Here!" program of talks at Rotary Clubs, 24 people have now signed up across most states. Sue Mackenzie from Queensland, who has spoken to many Rotary Clubs and raised a considerable amount of money for Polio Australia, has agreed to co-ordinate and mentor this group. If you would like to become a Speaker at your local Rotary Clubs, please contact Sue at sgmackenzie@bigpond.com. Apart from her great work with Rotary, congratulations are also in order for Sue's highly success fundraising event, *Fashion, Fiesta and Tapas* in Brisbane on the 9th of August (see Page 9). She raised a net of \$6,000 dollars for Polio Australia! This result is an inspiration to us all.

Considerable progress has been made with the planning for Polio Australia's *Australasia-Pacific Post-Polio Conference* in Sydney from the 20th–22nd September 2016, with more than twenty international and Australian speakers agreeing

Cont'd p3

From the Editor



Mary-ann Liethof
Editor

This is definitely a bumper edition, proving that Polio Australia has not been hibernating over our winter months. As highlighted in my article on page 1, a short trip to New Zealand was a wonderful opportunity to exchange information and 'freshen up'. It's easy to become a little insular when I spend so much time inside my own head.

There was also a quick visit to Sydney to participate in a truly inspirational meeting with Rotary District 9685 who are enthusiastically supporting a series of ten clinical practice workshops as a pilot for possible wider involvement across other Rotary Districts. More about this exciting program on page 12.

Various articles throughout this edition remind us that not all health problems relate to the late effects of polio, and to continue exploring symptoms in an informed way. Whilst we want our health practitioners to be knowledgeable about the LEOP, it's still your body.

If you haven't already heard about the 2016 Australasia-Pacific Post-Polio conference, you will

note the "Save the date" banners at the bottom of a couple of pages. Along with the amazing cast of confirmed Keynote Presenters, we have been receiving a steady stream of abstracts from eminent post-polio health specialists around the world. This conference will be a once-in-a-lifetime opportunity for Australian health practitioners and polio survivors alike to learn all about the Late Effects of Polio (LEoP) from the best the world has to offer. The [conference website](#) continues to be a work in progress but keep checking for the Preliminary Program which will be up in October-November 2015.

Although it doesn't appear in this issue, I would also encourage anyone interested in the latest clinical research being done in relation to LEoP/PPS to take a look at our [Polio Health website](#) and select 'Research'. You might be surprised what some institutes are looking into.

I'm getting this edition out a bit earlier than usual because I'm just about to head overseas for the month of September for a much anticipated holiday. When I return in October, we'll be into Polio Awareness Month, so I'm planning to participate in some serious R and R before then!

Please take your time and enjoy this read. 🌟

Mary-ann

From the President (cont'd)

to give Keynote presentations. A jewel in the crown is the agreement by NSW Health Minister, the Hon Jillian Skinner MP, to host and speak at the Conference Gala Dinner to be held in the spectacular NSW Parliament Strangers' Dining Room. The Steering Committee continues to meet to provide guidance to this event backed by an incredible amount of work behind the scenes by Mary-ann and Gillian Thomas. The Preliminary Program will be online in November, and you can find the latest on the conference by checking out the website www.postpolioconference.org.au. Having our own international conference in Sydney is a rare opportunity and I would encourage as many Australian health practitioners and polio survivors as possible to attend. 🌟

John

John Tierney demonstrating equipment at Polio NZ's Retreat



Retreat—New Zealand Style (cont'd)

Thursday 6th August 2015

John and I spent a lot of the morning trying to get our bearings in Hamilton – now that we had daylight – and figure out how to get to Houchen Retreat. Street signs were a bit 'random', which added an extra layer of challenge. However, we finally figured it out and reached our destination intact and still talking to each other . . .

Registration commenced at 1.00pm and we were all given a snazzy blue backpack with a few sweet treats, interesting nick-knacks, and other bits and pieces of useful information. The person tasked with organising all this was Polio NZ Board Member, Sue Griffin, who also managed to recruit some exceptional family and friends to help out with catering.

The afternoon sessions comprised presentations by:

- [Merv Arnesen](#) who makes shoes to order. Different size feet? He will make them to size for each foot. John actually ordered a pair, which will be sent to Australia.
- Helen Skedgwell from the [Public Trust](#) on the legal aspects of ageing, Enduring Power of Attorney, and Wills.
- Grant Pearse, a local Acupuncturist with a background in rehabilitation and 4 years spent in China. I put my hand up to be a volunteer pin cushion to see if he could make any impact on my chronic neck pain. The answer is "a bit", but obviously more time was needed than was available.

Dinner was a hearty beef casserole with mashed potatoes, broccoli and carrots, with apple crumble for desert, care of Sue's sister and friends.

This has been a promising start and tomorrow kicks off with stretching and exercises at 8.30am!

Friday 7th August 2015

Well, John and I didn't make it to the exercise and stretching including seated Tai Chi with Kathleen Paris from [Sports Waikato](#) – we blame the time lag . . .

However, we were in time for [Barry de Geest's](#) "A life less ordinary" session. Barry was a Thalidomide-baby and, now in his mid-50's, Barry reckons he's earned the right to be a 'grumpy old man'. He was both upbeat yet brutally honest about what and how things can get him down. Barry has fulfilled all the goals he set himself at

the age of 19, including driving independently, fathering a child, owning his own house(s) and starting up more than one business. He recently married, and his current business is custom built wheelchairs. Barry was definitely an inspirational speaker on goal setting and personal challenge.



After morning tea, there were two concurrent sessions:

- Resourcing Yourself - Energy Conservation and Mobility Aids. More later . . .
- Pharmaceutical Interactions with Helen Morton from the [Midlands Community Pharmacy Group](#), which is the session I went to. It's always good to be reminded of what we're putting into our body and why.

Both will be repeated on Saturday.

Following lunch, there were another two concurrent sessions to be repeated on Saturday:

- Self-expression and pain relief through painting, meditation and EFT/[tapping](#). This was led by Jill Illingsworth, an artist and psychotherapist who works with people to manage their pain. I attended this practical session, which a number of participants found helpful.
- A Bonsai demonstration was run by Melody, who has exhibited internationally.

Maggie Watson from disability service-provider '[Enable](#)' talked about the services they offer including financial support for home modifications, accessible vehicles, and aids and equipment.

The final session of the day was by an inspirational woman, Julie Hancox, who breeds and trains assistance dogs, primarily for children with autism. Her 'demo dog' was amazingly

Retreat—New Zealand Style (cont'd)

placid and tolerant, as it needs to be for children with special needs. Check out their [Facebook](#) page.

At 7.00pm, John Tierney gave a pre-dinner presentation on Polio Australia's work with Rotary, which was well received by our NZ brethren. We hope to work on joint health education projects in time.

Dinner was catered for and consisted of soup, followed by chicken and ham (an early Christmas?), baked potato and chips (for those who couldn't decide if they wanted to be naughty or not) – crumbed seafood, and vegetables. Oh, and because we hadn't had enough sweets at morning tea, lunch, and afternoon tea, we had pavlova **and** apple crumble! Of course, the age-old dispute of where the pavlova originated came up, but as we were on NZ turf, we let them win . . .

As well as this plentiful bounty and animated conversation – which you will find whenever you put a group of polio survivors in the same room – there was a wonderful round of songs from the [Male Voices Choir](#). Think *Welsh Male Choir* in Hamilton! Very good.

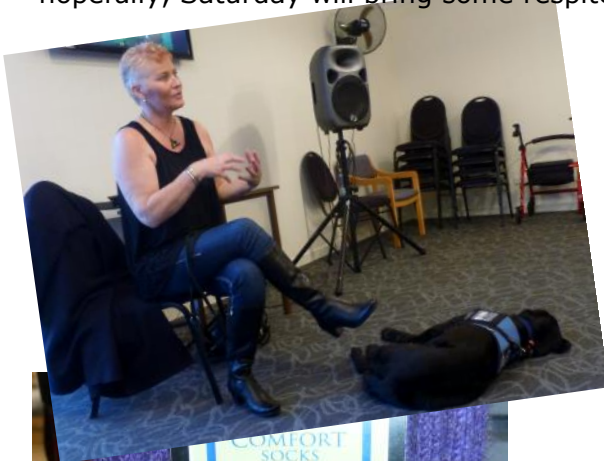
The weather has been showery all day so, hopefully, Saturday will bring some respite.

Saturday 8th August 2015

Today we started with a session called "Applied Kinesiology" with chiropractor, Dr Michael Hooker, who spoke about functional neurology and muscle testing. He had a very willing volunteer who said she was used to being a 'guinea pig'. In terms of the practice itself, the jury is still out for me.

I then attended the repeat session of Resourcing Yourself - Energy Conservation and Mobility Aids which comprised three interrelated sessions:

- Linda Hay is a qualified physiotherapist who was demonstrating a nifty mini trampoline called the '[Health Bounce Pod](#)', which is used for exercising and building core strength for people with limited mobility.
- Tanya Booth, an experienced Clinical Needs Assessor, who has previously worked with Life Unlimited, was available to discuss various assistive technology and mobility options.
- Toni Naera from [Life Unlimited](#) had a wide range of equipment and products for both demonstration and sale. These included bathroom and kitchen aids, sticks, cushions, and a couple of small scooters. I bought a pair of non-slip socks which took my fancy, and an inflatable cushion for use on hard seats.



Clockwise from top left:

- Assistance Dogs
- Male Voices Choir
- Acupuncture Demo
- Possum Socks!

Retreat—New Zealand Style (cont'd)

After lunch, John and I headed back to the hotel to deal with various business matters we needed to catch up on. However, we made it back in time to hear Parliamentarian, Barbara Stewart from NZ First, talk about health care issues and support (lack of) for polio survivors in NZ. The Board Members of Polio NZ are keen to raise awareness of the Late Effects of Polio amongst politicians and are looking into organising a group lobby visit to Parliament House on World Polio Day in October. Barbara indicated that she would help them out with this activity. Read more about Barbara on her [Facebook](#) page.

This was followed by a Board meeting which was open to all present. It was after that meeting that we discovered Polio NZ was considering employing a full time worker to progress their work. As Polio Australia discovered in 2010 after 2 years of purely volunteer activity, a paid employee will definitely help Polio NZ to move forward. We are looking forward to working together more closely in future.

Just before dinner, I gave a presentation on the [2016 Australasia-Pacific Post-Polio Conference](#), which I hope inspired a few more people to attend.

Then roast lamb for dinner. How quintessentially NZ! An 'unplugged' singer/acoustic guitarist, Cushla McCreesh, entertained us for an hour before those who were interested took off to watch a rugby match between NZ and Australia starting at 10.00pm local time. Can't wait to find out who wins.

Actually, I'm lying about that – I really don't care!

Sunday 9th August 2015

It was really hard to get out of bed this morning. Even though the bulk of the past few days has been spent sitting around listening, talking, and EATING, we are all showing signs of exhaustion – or maybe that's just my bleary eyes . . .

When we reconvened, we were treated to Rotarian Dennis Murdoch's picture presentation of his epic 1700 kilometre bike ride from Prague to Passau, during which time he raised awareness for the End Polio Now campaign. It certainly looked like a lot of fun was had by all.

This was followed by a demonstration on the mysteries of Facebook by Board Member, Gordon Jackman. We were pleased that the example he used was to enter the 2016 Australasia-Pacific Post Polio Conference on their webpage.

And before we knew it, it was time for group photos, and feedback for the next Retreat. With the success of this 'pilot', it looks like there will certainly be more Retreats for NZ in coming years.

In spite of only having 3 months to pull it together, whilst dealing with a number of other highly stressful events occurring at the same time, and never even having attended a Retreat herself, Sue Griffin managed to come up with the goods. The overwhelming feedback and discussion amongst the participants was that they all got a lot out of the 4 days they were together – especially the 'togetherness' part of it!



Rotarian, Dennis Murdoch

John and I then drove 2 hours back to Auckland through episodes of torrential rain and even hail. Very exciting when you're not 100% sure where you're going. So if I hadn't already been exhausted, I certainly would have been after that experience, considering I was the designated driver. But John helped sooth my jangled nerves by negotiating an entry for me into the Emirates Lounge as his guest, even though we were on different flights with different airlines. What a wonderful thing to have such 'influence'. It's a lifestyle I'd like to become accustomed to, but I guess I'll just have to keep dreaming until I win the Lottery.

We were very pleased to have had the opportunity to join in with our Kiwi cousins for their Retreat, and everyone there made us feel most welcome. I believe we are all now very comfortable with sharing our experiences, ideas, and ambitions for better health and support services for polio survivors in both countries.

So although Australia won the rugby match on Saturday night (apparently!), we got out alive and parted as firm friends with full intentions of meeting again soon. 🌟

Walk With Me Activities

While it is only a short walk for some, it's a real challenge for others. Walk With Me redefines the traditional notion of an event challenge. It's not about running faster, swimming further or cycling longer distances. It's a 2km or 4km walk challenging us all to take the time to walk alongside people of all abilities.

Walk With Me is an opportunity to support and celebrate the diversity within our community in an inclusive and festive environment.

Walk With Me is an acknowledgement that 1 in 5 Australians is challenged by a disability, and recognises the inspirational attitudes and achievements of 20% of our population.

Walk With Me is made possible by a partnership between Ability First Australia, its 12 Charity Partners, and major sponsor Dick Smith.

Bring your family, friends and workmates along to Walk With Me 2015. Details of events in each state, together with registration and sponsorship options can be found here: www.walkwithme.org.au



2014 Parramatta Walk with Gillian Thomas (sitting), John and Pam Tierney (standing) and friend

This year, Polio Australia will be represented at the following walks:

ACT: Thursday 15 October—see details below

South Australia: [Polio SA](#) and Novita—Sunday 30 August in Botanic Park, Adelaide

New South Wales: [Polio NSW](#) and Northcott—Wednesday 16 September starting Prince Alfred Square and finishing Centenary Square near Parramatta Town Hall, Parramatta

Victoria: Polio Australia and Scope—March 2016 in Bendigo. More details to come.

In 2014, Polio Australia and its state-based polio network members raised a grand total of \$15,686 and we are hoping to do even better this year!

Note: Donations will still be accepted until the 31st of December.

Walk With Me in Canberra for Polio Awareness Month

Polio Australia is adding an extra 'Walk' in October this year, and inviting our Parliamentary Patrons and Friendship Group members to participate.

Like the previous Polio Awareness Month "We're Still Here!" campaigns, we are asking interested post-polio participants to assemble in the Marble Hall at the entrance of Parliament House in Canberra on Thursday 15th October at around 12.30pm for a 1.00 pm start.

We will be inviting Senators to 'walk' with us from the Parliament House entrance around to the Senate entrance and back to the Marble Hall,

and the MPs will be asked to walk to the House of Representatives entrance and back. The total distance for either of these walks is 1 km.

Polio Australia's post-polio team will be divided, with half each joining either the Senators or MPs.

To recover, we will be inviting all 'walkers', including the Parliamentarians, to refreshments in the [The Queen's Terrace Café](#) above the main entrance.

Help us raise awareness for Polio Awareness Month, whilst raising funds for the work of Polio Australia, by joining in this walk. For further details and to Register or sponsor the team, please check [here](#).

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 May to 30 July 2015:

Hall of Fame

Name	Donation
Dr John & Pam Tierney	\$3,250
Dusty Peck	\$1,000
Total—\$4,250	

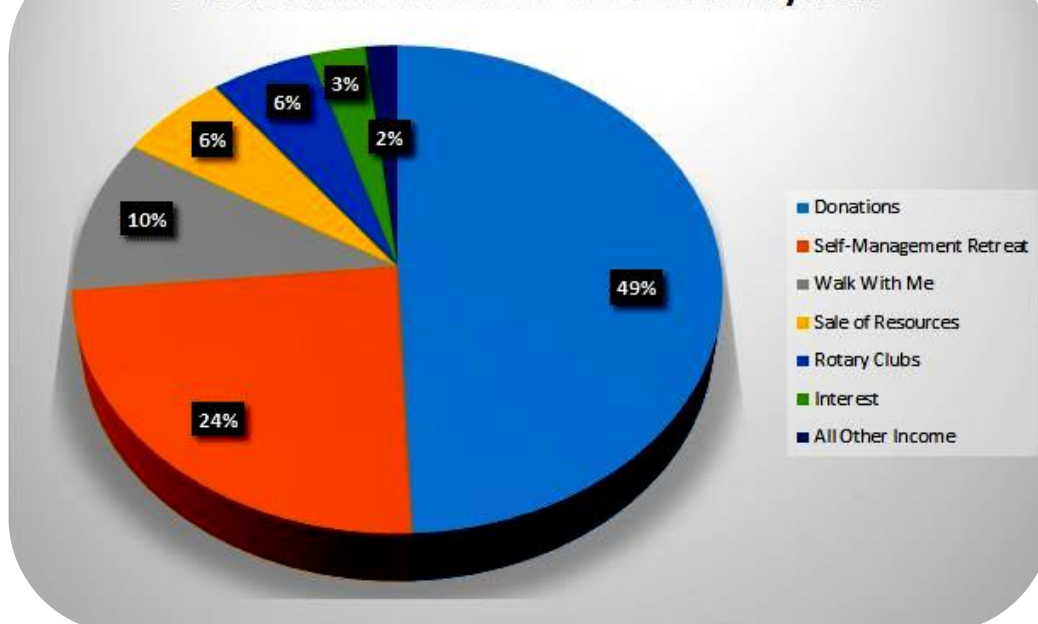
General Donations

Names		
Jill Burn	R&J Mudge	Gillian Thomas
Lyn Lillecrapp	Dorothy Robinson	Anonymous
Total—\$1,439		

Rotary Donations

Name	Donations
Rotary Club of Bribie Island (Qld)	\$1,000
Rotary Club of Mackay (Qld)	\$1,000
Rotary Club of Rutherford (NSW)	\$1,000
Rotary Club of Belmont (NSW)	\$500
Rotary Club of Greenhills-Maitland (NSW)	\$500
Rotary Club of North Ryde (NSW)	\$500
Rotary Club of Waratah (NSW)	\$200
Total—\$4,700	

Polio Australia Income Sources 2014/2015



A Fun Day of Fashion, Fiesta and Tapas!

By Dr Margaret Peel

A sell-out fundraising event for Polio Australia organised by Sue and Graeme Mackenzie (with the assistance of Jane Young, Rosemarie Davidson, Jan Williams and Sarah Hutson) was held at the newly renovated Brunswick Hotel in New Farm in Brisbane on Sunday afternoon, 9th August.

Among the guests were Queensland ALP MPs Grace Grace and Joe Kelly (represented by Sue Adams), and Brisbane City Councillor for the Central Ward that includes New Farm, Vicki Howard. Every attendee received a copy of Polio Australia's pamphlet, "We're Still Here!".

The entertainment included Flamenco Dancing by Yolanda Fernandez and her two daughters, fashion parades by Fashion Houses, SFH and Peach Starlight, display and sales by Lorraine Lea Linen Shop, and Tarot Card Reading by Maria, all while the guests consumed champagne and tapas.

Some \$3,000 worth of goods were raffled and a silent auction was conducted for several items of particularly high value.

The event was a great success and most enjoyable. Special thanks on behalf of Polio Australia were conveyed to Sue and Graeme by Board Member, Margaret Peel.

Note: The 95 people in attendance raised a healthy total of \$8,682/\$6,738 nett. 🇦🇺



Sue (far left) with her fantastic team of volunteers



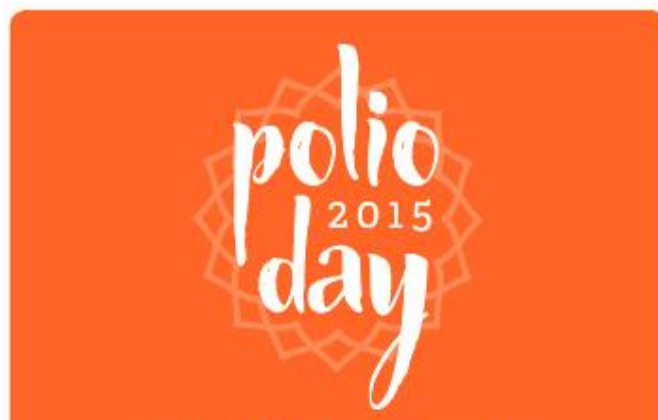
Fun Fashions!



Left: Flamenco Dancing / Above: Happy faces say it all

Polio Day Activities

 <p>Not for Profit National Peak Body</p> <p>Celebrate Bribie Island Qld</p> <p>\$50 Per Head</p> <p>PRIZES</p> <p>Raffles Auction</p> <p>Bribie Island Hotel</p> <p>29 Sylvan Beach Esplanade Bellara Qld 4507 Ph: 07 3408 7477</p>	<p>Polio Australia Representing polio survivors throughout Australia</p> <p>Rotary Bribie Island</p> <p>Awareness Knowledge Information Supporting the survivors of Polio</p>	
	<p>World Polio Day Saturday 24th October 2015</p>	
	<p>SPECIAL GUEST Gold Coast BENJI</p> 	<p>ENTERTAINMENT The amazing soloist ONE VOICE "KELSY"</p>  <p>Kelsy Vocals/Drumming</p>
	<p>Luncheon - Saturday 24th October 2015 12 noon to 3.30 pm</p> <p>Tickets available for \$50 each - phone Bill or Peter on 0403 686 998 Online tickets can be purchased by credit card at www.trybooking.com/IWSN</p> <p><i>Net proceeds donated to support the work of Polio Australia</i></p>	



Polio Day in Victoria will take place on Saturday 24 October 2015 at Springvale Town Hall, 297-405 Springvale Road, from 10.30am to 3.30pm.

The theme of the day is: ***Team Polio 2015—making sense of change.*** This day will focus on how polio survivors deal with change not only within themselves, but external forces impacting on them such as state and federal services providing care and equipment.

To Register [Download and complete the form](#) and return by Friday 9 October to:

Georgie Stayches
Fetching Events & Communications

Email: georgie@fetchingevents.com.au

For more information about World Polio Day at the Bribie Island Hotel (Qld), contact Bill Peacock at wpeacock658@gmail.com. Purchase tickets online at www.trybooking.com/



Spinal Injuries Australia, Brisbane will have renowned Queensland Post Polio specialist, Dr Peter Nolan (*pictured left*), as their key note speaker for World Polio Day commemorations on 23 October 2015 commencing at 10.15am.

Dr Nolan will present "A reflection of the mind, body, soul relationship of the journey with polio."

For further information please contact Jeanette Kretschmann on (07) 3391 2044 or jkretschmann@spinal.com.au



**2016 Australasia-Pacific
Post-Polio Conference**
Polio - Life Stage Matters

**20-22
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2016**

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**SAVE
THE
DATE**

www.postpolioconference.org.au

Polio Day Activities (cont'd)

The [British Polio Fellowship](#) has announced that several famous buildings and structures across Great Britain are to be illuminated with the colours of The British Polio Fellowship's Post Polio Syndrome (PPS) Day Emblem. (PPS Day this year is on 22 October.)

The pre-publicity event will see well-known landmarks in a different light in an attempt to draw attention to the issues that surround those with the late effects of Polio and PPS, thought to be around 120,000 people in the UK. This number is believed to be similar to the number of people suffering from Parkinson's or Motor Neurone diseases, but PPS only receives a fraction of public and medical awareness.

It has been announced that the first landmark to be lit up will be Gateshead Millennium Bridge, with others set to follow. The British Polio Fellowship has put a call out to authorities of landmark buildings throughout Britain that would like to be involved to get in contact to help spread the message of PPS.

"The chance to capture the entire nation's attention with this campaign is extremely exciting and fruitful," said Ted Hill, CEO of The British Polio Fellowship. "We're extremely delighted to be able to announce Gateshead Millennium Bridge as the first landmark building to sign up. I'd like to extend my sincerest gratitude to Gateshead Council and its locals, and in the process encourage other Councils and their landmarks to come forward."



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LEoP Clinical Practice Workshop Series in Sydney

[Rotary District 9685](#) (Sydney Harbour to the Central Coast of NSW) continues to progress its commitment to fund and work with Polio Australia to deliver a pilot program of The Late Effects of Polio (LEoP) Clinical Practise Workshops, providing local health care professionals with peer education and resources to work with the post-polio body

We are now working towards finalising the details of the series of ten LEOp workshops which are scheduled to take place between November this year and March 2016. An agreement has been made with [Advance Rehab Centre](#) (ARC Health) to provide peer educators to facilitate this program. ARC Health specialises in neuro-rehabilitation and the Director, Melissa McConaghy, is a member of Polio Australia's Clinical Advisory Group.

In coming months, these LEOp workshops will be promoted throughout Rotary District 9685 Club areas, with health practitioners being able to book in to any of the ten workshops through the Polio Health website: www.poliohealth.org.au/professional-development-workshops.

If this pilot is a success, PDG Bob Aitken, and District Governor Gina Growden, and their team, plan to promote a similar series of LEOp Clinical Practice Workshops in ALL Rotary Districts around Australia and New Zealand. This is a very exciting program and Polio Australia is delighted that Rotary District 9685 have embraced this workshop series as one of their projects.

We believe that Rotary working to assist polio survivors is 'closing the circle' with the early days of starting up the 'Crippled Children's Associations' in Australia—predominantly for children recovering from polio—through to the excellent contribution they have made with the world polio eradication efforts.

Those children who survived last century's polio epidemics are once again needing support to help manage the Late Effects of Polio. Providing LEOp Clinical Practise Workshops for health professionals will ensure that they receive the appropriate care and management to maintain the best quality of life possible. Thanks again Rotary! 🌟

- Ed

Northern Gold Coast Seniors Expo



L-R: Brian (Rotary) Diane, Stuart Roberts MP (holding [Benji](#)), Lyn, and Sylvia

The sixth Northern Gold Coast Seniors Expo was held on the 29th of July and offered the local seniors community an opportunity to find out what local private and government services can do for them. The Seniors Expo is an initiative of local Federal Member Stuart Robert MP and is free to attend.

This year's Expo was held at the Runaway Bay Indoor Basketball Centre with over 170 exhibitors plus presenters, demonstrations, lucky door prizes and special guests.

Also in attendance were Lyn Glover, Facilitator of the Gold Coast Post Polio Network together with members Diane and Sylvia.

Brisbane-based Sue Mackenzie also called in to help out on the Rotary Stall that Lyn and her team were invited to share. Polio Australia supplied a number of brochures which were handed out on the day. A big THANK YOU to all who participated. 🌟

Exhibit for Disability Rights

By Dellaram Vreeland

Source: [The Courier](#) – 7 July 2015

AN EXHIBITION exploring campaigning for disability rights was launched in Ballarat last week.

Entitled *Grassroots Democracy: The Campaign for Disability Rights*, the exhibition is on show at the Museum of Australian Democracy at Eureka. (Until July 29)

Exploring the deinstitutionalisation of the 1970s, the rights-based activism of the 70s and 80s and the recent introduction of the National Disability Insurance Scheme, the retrospective show is exhibited both in the museum and [online](#).

Grassroots Democracy guest curator Ashley Heenan said the show aimed to start conversations about the disability rights movement in Australia by exploring key milestones of change and introducing the people behind that change.

Ed Note: Post-Polio Victoria's Vice President, Margaret Cooper, (pictured above) was amongst those featured in the exhibition. Congratulations Margaret, we have all benefited from your efforts! 🌟



Polio Alert Is Critical



By Liz Telford and Fleur Rubens
Post Polio Victoria Inc

Source: [theage.com.au](#)
Comment—18 August 2015

Julia Medew highlights errors in clinical management that have occurred in our hospitals with some devastating outcomes ("Hundreds of patients' deaths preventable", 15/8).

A lack of medical knowledge is another cause. Here is a real example. In 2011, a man died unexpectedly in a major hospital a month after surgery. He had a history of polio. A surgical error considered minor (as it is for someone without post polio) combined with inappropriate post-surgery care (due to

hospital ignorance of post-polio management) resulted in respiratory failure. The cause of death was given as "post polio", although it was not the disease process but clinical management that caused this man's preventable death.

Anyone who contracted polio, whether paralysed or not (an estimated 400,000 Australians) may develop post polio, a condition that may affect the central nervous and respiratory systems.

One Victorian hospital now has a polio medical alert for patients known to have had polio. All hospitals need to do the same, and patients should alert staff if they ever contracted polio. Despite the successful global polio eradication campaign, post polio will be around for decades to come and hospital staff must be educated. 🌟

What's On In Your State At A Glance

ACT

2015 Polio Awareness Month: Thursday 15 October 2015, 12.30pm for 1.00pm to 2.00pm "Walk With Me" fundraising and awareness raising event at Parliament House, Canberra. More details can be found on the "[Walk With Me](#)" website including Registration and Sponsorship.

Victoria

2015 Polio Day: Saturday 24 October 2015, 10.30am to 3.00pm, at the Springvale Town Hall. Polio Network Victoria, supported by Independence Australia. The theme of the day is: **Team Polio 2015—making sense of change**. This day will focus on how polio survivors deal with change not only within themselves, but external forces impacting on them such as state and federal services providing care and equipment. To Register [Download and complete the form and](#) return by Friday 9 October to [Georgie Stayches](#).

AGM: [Post-Polio Victoria](#) will be holding their Annual General Meeting at 11.00am on Monday 23rd November 2015 at the Disabled Motorists Association, 2A Station Street, Coburg, Victoria. Find out about PPV's advocacy work over the past year and join in the discussion. Refreshments provided. All welcome! Email [Post Polio Victoria](#) for details.

New South Wales

Walk With Me: Polio Australia will be holding its third "[Walk With Me](#)" fundraiser in Parramatta in conjunction with the Northcott Society. By supporting the Walk, you will also be supporting [Polio NSW](#). Registration and Sponsorship details can be found [here](#). **When:** Wednesday 16 September, 2015 **Time:** Meet for walk at 11am, entertainment, information and food stalls between 12pm–2pm **Where:** Meet at Prince Alfred Square and walk down Church Street to Centenary Square (near Parramatta Town Hall).

LEoP Clinical Practice Workshops: The Late Effects of Polio (LEoP) Clinical Practice Workshops will be taking place at ten venues around Sydney and surrounds between November 2015 and April 2016, providing local health care professionals with peer education and resources to work with the post-polio body. Details will be available online on the [Polio Health website](#).

2016 Australasia-Pacific Post-Polio Conference: 20-22 September 2016 at the Four Seasons Hotel, Sydney. All details can be found on the [conference website](#).

Queensland

2015 Polio Day: [Spinal Injuries Australia](#), Brisbane will have renowned Queensland Post Polio specialist, Dr Peter Nolan, as their key note speaker for World Polio Day commemorations on 23 October 2015, commencing at 10.15am. Dr Nolan will present "*A reflection of the mind, body, soul relationship of the journey with polio.*" For further information contact [Jeanette Kretschmann](#) or Ph: (07) 3391 2044.

2015 Polio Day: A [Polio Day Luncheon](#) is being held on Saturday 24th October 2015 from 12 noon to 3.30pm at the Bribie Island Hotel, 29 Sylvan Beach Esplanade, Bellara Qld 4507. There will be prizes, raffles, an auction, and entertainment by the amazing soloist 'Kelsy'. For more information, contact [Bill Peacock](#). Tickets are available for \$50 each and can be purchased online by credit card at [www.trybooking.com/IWSN](#) with nett proceeds donated to support the work of Polio Australia.

South Australia

Walk With Me: Polio South Australia is co-hosting Walk With Me 2015 on Sunday, August 30 in Botanic Park, Adelaide. Walk With Me is Australia's leading event connecting people of all abilities. Walk With Me will take participants on a fully-accessible 2.5km walk from Botanic Park through the scenic Adelaide Botanic Gardens. The walk will finish at the Adelaide Zoo, where all registered participants will receive free entry to enjoy the remainder of the day exploring the sights, sounds and animals at the Zoo. Registration and Sponsorship details can be found [here](#).

Don't Blame PPS For Everything

By Stephen Pate

Source: Oye! Daily Life - 7 August 2015



Post-Polio Syndrome can mask life threatening health problems like heart disease.

Post-Polio Syndrome (PPS) can dominate your life but it may not be your only health problem. In fact, post-polio can mask life threatening health issues. Pain, muscle weakness, fatigue and sleep disorders are common to Post-Polio and a number of other conditions.

According to the Mayo clinic, *"common signs and symptoms of post-polio syndrome include: progressive muscle and joint weakness and pain, general fatigue and exhaustion with minimal activity, muscle atrophy, breathing or swallowing problems, sleep-related breathing disorders, such as sleep apnea and decreased tolerance of cold temperatures. In most people, post-polio syndrome tends to progress slowly, with new signs and symptoms followed by periods of stability"*.

When someone gets Post-Polio Syndrome they and their doctors can tend to blame everything else on PPS. That may seem logical but it can be wrong.

"As a post-polio survivor I have been fooled more than once", wrote Bruce Lambert in ["Is It Post-Polio or Something Else"](#) (Post-Polio Health). *"My doctors too, even the good ones"*.

The devilish thing is that Post-Polio is often misdiagnosed as something else – aging, Chronic Fatigue Syndrome or a number of conditions with weakening muscles and persistent pain.

However, once Post-Polio Syndrome is confirmed, it becomes the reason for every new symptom. We want to believe that because that simplifies life.

In Bruce Lambert's story, a new groin pain was not Post-Polio: it was spinal arthritis which took multiple MRI's and X-rays to diagnose.

Coronary Heart Disease and Post-Polio

Fatigue and shortness of breath are also signs of coronary heart disease or CHD. Arteries clogged with cholesterol reduce the amount of oxygen in the blood and create weakness, shortness of breath and muscle pain in the extremities like arms and legs.

Fatigue is symptomatic of a Post-Polio diagnosis. Certainly PPS can also contribute to deconditioning and more weakness. However, the cause of new weakness and pain may be *"cardiovascular disease...caused by narrowed, blocked or stiffened blood vessels that prevent your heart, brain or other parts of your body from receiving enough blood"*. [Mayo Clinic](#)

An ounce of prevention is worth a pound of cure. Getting a proper diagnosis before a heart attack is better than after. First, some heart attacks kill you without warning. Secondly, even if you survive a heart attack, the recovery process is long and slow.

If you find it hard to climb a ladder or do tasks that previously were possible, you may have CHD and be a heart attack candidate. See your doctor and get your cholesterol, blood pressure and other indicators checked.

The traditional tests for heart attack or CHD are poor predictors of heart attacks. Everyone knows someone who passed their stress test and died within months from a massive fatal heart attack. There is a new test that can more accurately predict your heart condition called the [Coronary Calcium Scan](#). Like an MRI, it can predict if you have a build-up of plaque in your arteries and risk a heart attack.

"A coronary calcium scan is a fairly simple test. You'll lie quietly in the scanner machine for about 10 minutes while it takes pictures of your heart. The pictures will show whether you have calcifications in your coronary arteries. A coronary calcium scan is most useful for people who are at moderate risk for heart attacks."

Don't Blame PPS For Everything (cont'd)

You or your doctor can calculate your 10-year risk using the [Risk Assessment Tool](#) from the National Cholesterol Education Program". [Australian's may prefer to look at [this Australian website](#).]

If you have Post-Polio Syndrome and are dependant on a wheelchair or crutches for mobility, it is highly likely you are at risk. Our bodies are meant to be in motion and that becomes more difficult for PPS survivors. There are things you can do to avoid a heart attack like take statins and blood pressure medications, get rid of the stress in your life, lose weight to shed those dangerous extra pounds and try to get into an exercise program.

Full article [here](#). ●

ICD Codes

Source: [Polio Place Website](#) - Updated August 2015

The International Classification of Diseases is a clinical cataloguing system of alphanumeric designations given to every diagnosis, description of symptoms and cause of death attributed to human beings.

It means that each diagnosis a human being may be given has a code, a numbered designation, that goes with it. That code means that every medical professional in the United States and many other parts of the world will understand the diagnosis the same way.

Many countries use the tenth edition (ICD-10). The United States will implement the ICD-10 on October 1, 2015.

Relevant polio and post-polio codes from the ICD -10 are:

Z24 - need for immunization against poliomyelitis

[A80-A80.9](#) - acute poliomyelitis

[B91](#) - Sequelae of poliomyelitis

[G14](#) - Postpolio syndrome

Visit Post-Polio Health International's Polio Place website for more on ICD Codes and many more facts on polio and post polio: www.polioplace.org ●

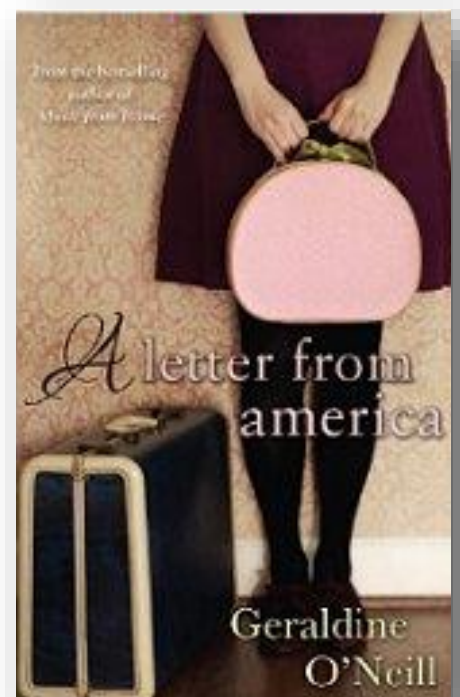
A Letter From America

Information provided by John MacFarlane, President, European Polio Union

Geraldine O'Neill is the pen name of a member of the Post Polio Support Group of Ireland. In her eleventh novel, "A Letter from America", she draws directly on her own experiences of being a polio survivor as well as those of others of the PPSG group to develop the character of Angela Tracey, one of three sisters at the heart of the action.

Geraldine, although born in Scotland, has her heritage and cultural background firmly rooted in the Midlands of Ireland. If you want a good holiday read, as well as to soak up something associated with Ireland, it's well worth giving this book a go.

"A Letter from America" is published by Poolbeg Press Ltd and is available in paperback and Kindle (ISBN 978-1-78199-189-3) from national [Amazon websites](#). Some of her previous books, all of which have an Irish link, have been translated into other languages. ●



New Resources to Help Communication

New Resources will Help Communication Between Consumers and Health Professionals

Source: [Painaustralia](#) e-News Issue 55 – 14 August 2015

[NPS MedicineWise](#) has launched a range of chronic pain resources for consumers and health professionals, to help facilitate conversations about chronic pain and encourage a multimodal approach to treatment.

Easily digested they are designed to fit in with health professionals' busy schedules, and offer a sound resource for patients, particularly those who have just been diagnosed with chronic pain or who have a poor understanding of the condition.

Developed in conjunction with Painaustralia, Chronic Pain Australia, Arthritis Australia and the

Australian Pain Management Association, consumer tools include chronic pain communication tool, my pain diary and the chronic pain knowledge hub.

For health professionals, there a suite of new learning products as part of their chronic pain professional development program. They include:

- Educational visits on chronic pain (one-on-one or small groups)
- Detailed online information about chronic pain
- Health professional publication MedicineWise News 'Chronic Pain'
- Clinical eAudit
- A new online case study: Chronic pain opioids and beyond

If you would like to find out more, or to download information, visit the [NPS MedicineWise](#) chronic pain portal. 🌐

My Health Apps

[myhealthapps.net](#) brings together the world's favourite healthcare apps – *tried and tested by people like you*.

[myhealthapps.net](#) gives public, patients and carers a quick and easy way to find trusted apps to:

- make a difference to your health
- help you support someone you care for

Each app is recommended by healthcare communities from all over the world, including:

- empowered consumers
- patients
- carers
- patient groups

- charities and other not-for-profit organisations

[myhealthapps.net](#) works together with this network to:

- highlight best practice in health app development
- highlight the unmet needs of public, patients and carers to app developers
- bridge the gap between public, patients and carers with app developers to improve the relevance, quality and health impact of apps

The result is the best healthcare apps, recommended by empowered consumers, patients and carers. 🌐

RACV Offering Roadside Wheelie Assistance

By [Kymberly Martin](#)

Source: [freedom2live.com.au](#) – 15 April 2015

The RACV is offering a roadside assistance package to wheelchair and scooter users when devices are immobilised. If the problem is from mechanical failure, flat tyre or even a flat battery the RACV will assist with either getting the user mobile again, or make arrangements to get the user and the device home or to a place of repair.

The package allows for eight calls a year. For non-members there is an initial cost of \$102.50 (includes an establishment fee of \$54) with an ongoing cost of \$48.50 per annum. New subscribers under 21 are exempt from the establishment fee. There are various discount packages available to RACV members. For more information visit: [www.racv.com.au](#) 🌐

50% of Australians Battling Chronic Disease

Media Release: The Hon Sussan Ley MP
Minister for Health
Minister for Sport

Source: [Department of Health Media Release](#)
—12 August 2015

The need for Primary Health Care reform has been highlighted with the release of new statistics that show half of all Australians have at least one chronic disease.

Minister for Health Sussan Ley said the new figures backed the Abbott Government's decision to set up a Primary Health Care Advisory Group, which is travelling the country over the next three weeks to discuss primary health care reform.

Ms Ley said the Abbott Government was committed to reforming primary health care with the release last week of an options discussion paper '*Better outcomes for people living with Chronic and Complex Health Conditions through Primary Health Care*'. Australians can comment on the discussion paper and supporting documents or fill out the consultation survey at the [Department of Health's website](#).

"As our population ages, we know that the prevention and treatment of chronic disease is an increasing challenge for the health system and Australians generally," Ms Ley said.

"The Abbott Government is committed to engaging with health professionals and patients to reform the way we treat people with chronic and complex conditions.

"It is concerning these stats show not only do half of all Australians have a chronic disease but one-in-five have at least two of the most common eight chronic diseases including diabetes, cardio-vascular disease and mental health conditions."

Ms Ley said the discussion paper considered possible reform options which would inform the government's development of a healthier Medicare to keep people out of hospital longer.

"We are committed to finding better ways to care



for people with chronic and complex conditions and ensure they receive the right care, in the right place, at the right time," Ms Ley said.

Ms Ley said the Primary Health Care Advisory Group, led by former AMA President Dr Steve Hambleton, had developed the discussion paper and would hold public consultations across Australia over the next three weeks to finalise its recommendations to Government.

"I encourage all Australians including patients, health professionals and interested parties to look at the options included in the discussion paper and provide their feedback as we work hand-in-hand to deliver a primary health care system that better looks after Australians earlier."

Ms Ley said the Primary Health Care Advisory Group would seek further feedback through public consultations in Sydney, Western Sydney and Dubbo before moving on to Melbourne, Geelong, Hobart, Brisbane, Cairns, Rockhampton, Adelaide, Alice Springs, Darwin, Perth and Broome.

Following the public consultation, the Primary Health Care Advisory Group will develop specific recommendations for Government by the end of the year. For the full report and statistics visit the [AIHW website](#).



**2016 Australasia-Pacific
Post-Polio Conference**
Polio - Life Stage Matters

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SEASONS
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SYDNEY**

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THE
DATE**

The First Iron Lung

By Lily Barback, Associate Editor

Source: www.laboratoryequipment.com
- 29 July 2015



The iron lung ward at Rancho Los Amigos Hospital around 1953

On July 29, 1929, the first electric respirator, or iron lung, was installed in Bellevue hospital to

fight a polio epidemic. The machine was made from two vacuum cleaners and worked on negative pressure. It surrounded a person's body save for the head.

The machine created negative pressure outside a patient's body, forcing an expansion for the rib cage and an inhale of air from the person's nose or mouth outside the device. A return to ambient pressure caused the deflation of the lungs and an exhale. It was created at Harvard by Phillip Drinker and Louis Agassiz Shaw.

John Mayrow first considered the idea of an external negative pressure in 1670. His version used bellows to change the pressure. Models were built to be pumped by hand. The machine created by Drinker and Shaw was the first to run on electricity. After saving the life of a 10-year-old at death's door it became popular and widely accepted.

Read article online [here](#).🌟

Meet The Heroes And Villains of Vaccine History

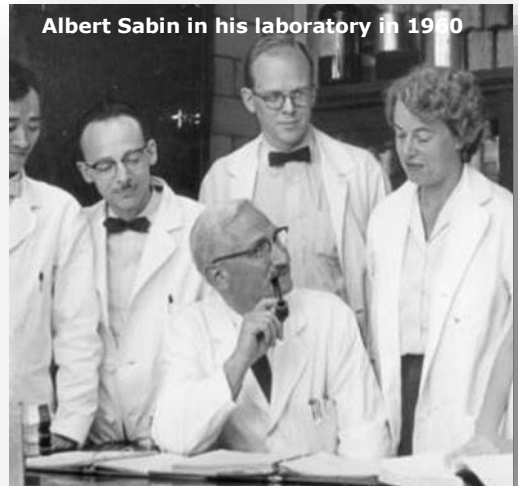
By Jeffrey Kluger

Source: Time – 29 July 2015
<http://time.com/3977055/vaccine-heroes-villains/>

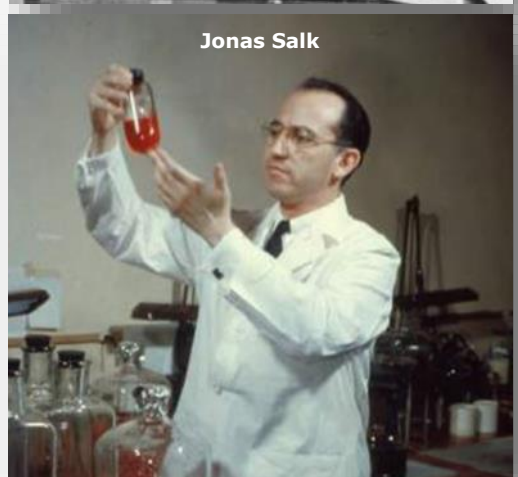
A California legislator who faces a recall campaign for his support of a law mandating vaccinations is just one of the heroes in the history of vaccines. Alas, there are villains too.

Jonas Salk and Albert Sabin didn't much care for each other. The older, arid Sabin and the younger, eager Salk would never have been good matches no matter what, but their differences in temperament were nothing compared to a disagreement they had over science. Both researchers were part of the National Foundation for Infantile Paralysis—later dubbed the March of Dimes—and both were trying to develop a polio vaccine. Sabin was convinced that only a live, weakened virus could do the trick; Salk was convinced a newer approach—using the remains of a killed virus—would be better and safer. Both men turned out to be right. Salk's vaccine was proven successful in 1955; Sabin's—which was easier to administer, especially in the developing world, but can cause the rare case of vaccine-induced polio due to viral mutations—followed in 1962. Both vaccines have pushed polio to the brink of eradication. It is now endemic in only three countries—Afghanistan, Pakistan and Nigeria—and appears, at last, destined to follow smallpox over the extinction cliff. 🌟

Albert Sabin in his laboratory in 1960



Jonas Salk



Exercise May Reduce Mortality In Elders

By Laird Harrison

Source: Medscape Medical News - 4 August 2015

Official guidelines should set lower exercise targets for people older than 60 years than for younger adults, a meta-analysis shows. This population can reduce its risk for death by about 22% with only half the recommended 150 minutes per week of moderate-intensity exercise, according to the new report.

"Based on these results, we believe that the target for physical activity in the current recommendations might be too high for older adults and may discourage some of them", writes David Hupin, MD, from the Centre Hospitalier Universitaire de Saint-Étienne, Hôpital Nord, Service de Physiologie Clinique et de l'Exercice, Saint-Étienne, France, and colleagues.

They published their findings [online](#) August 3 in the *British Journal of Sports Medicine*.

The physical activity [guidelines](#) of the US Department of Health and Human Services do not distinguish between older and middle-aged adults, except to say that older adults limited by 'chronic conditions' should *"be as physically active as their abilities and conditions allow"*, the researchers note.

More than 60% of older adults find 150 minutes per week of moderate to vigorous exercise too demanding, the researchers write. Examples of moderate to vigorous activities include brisk walking, cycling, swimming, and gymnastics.


The researchers wanted to know whether people older than 60 years could benefit from aiming at a lower target, so they searched the published literature to find out what levels of activity produced the most benefits in this population. Of a total of 835 relevant studies, they found nine suitable for analysis. These studies involved a total of 122,417 participants who were monitored for an average of around 10 years. During this period, 18,122 patients died.

The greatest benefit seemed to accrue to those who went from doing nothing, or only a minimal amount of physical activity, to doing more.

Older women appeared to benefit more than older men from exercise, but the researchers speculate that this finding could stem from men overestimating their physical activity and women underestimating it.

From these findings, the researchers conclude that 250 MET minutes, which corresponds to 75 minutes per week of moderate to vigorous physical activity, was a more reasonable goal for adults older than 60 years. That is only 15 minutes per day 5 days a week, they note.

"The widespread diffusion of this message will encourage more older adults to include even low doses of [moderate- to vigorous-intensity physical activity] in their usual daily activities, without experiencing high levels of fatigue or of pain", the researchers conclude. *"This message should be relayed by general practitioners who play a key and essential role in promoting physical activity behaviour in older adults".*

Br J Sports Med. Published online August 3, 2015. [Full text](#) 



Vitamin D And Weight Loss In Older Women

By Megan Brooks

Source: Medscape - July 01, 2015

Vitamin D supplementation augments the benefits of weight loss on systemic inflammation linked to cancer and chronic disease, according to new research.

In the year-long study of older overweight women with insufficient vitamin D levels, weight loss coupled with vitamin D supplementation had a greater effect on reducing levels of the proinflammatory cytokine interleukin (IL)-6 than weight loss alone.

"Evidence suggests that overweight individuals have lower levels of vitamin D because it's sequestered in fat depots, leading to lower bioavailability", said lead author Catherine Duggan, PhD, from Fred Hutchinson Cancer Research Center in Seattle.

It is possible that *"weight loss leading to fat loss, releasing stores of vitamin D, would have an additive effect on the vitamin D₃ supplements (which themselves aren't being sequestered)",* she told Medscape Medical News. *"We already know that weight loss reduces levels of inflammation, so this effect, plus the added benefit of vitamin D₃ supplements and the increased bioavailability of vitamin D₃, reduces IL-6 levels by a measurable level".*


The study was [published online](#) April 23 in *Cancer Prevention Research*.

"Clinicians should encourage maintenance of a healthy weight to reduce chronic inflammation and its associated effects. Overweight individuals should be tested for vitamin D deficiency/insufficiency and supplementation advised as necessary", Dr Duggan suggested.

However, a researcher who has studied the effects of vitamin D on inflammatory biomarkers is not convinced. The effect seen may be due to weight, said Paulette D. Chandler, MD, MPH, from Brigham and Women's Hospital and Harvard Medical School in Boston, who was not involved with the study.

Chronic Inflammation as a Protumorigenic State

Chronic inflammation is thought to represent a protumorigenic state. Previous studies have shown that losing weight can reduce inflammation, and there is some evidence that taking vitamin D supplements can have a similar effect in people with insufficient levels of the nutrient. Dr Duggan and her colleagues report that their study is the first to assess whether adding vitamin D can boost the effect of weight loss on inflammatory biomarkers.

Cancer Prev Res (Phila). Published online April 23, 2015. [Abstract](#) 

Mediterranean Diet May Preserve Brain

By Megan Brooks

Source: Medscape Medical News /Neurology - August 07, 2015

The Mediterranean diet may help preserve structural connectivity in the brain in older adults, results of a French study hint.

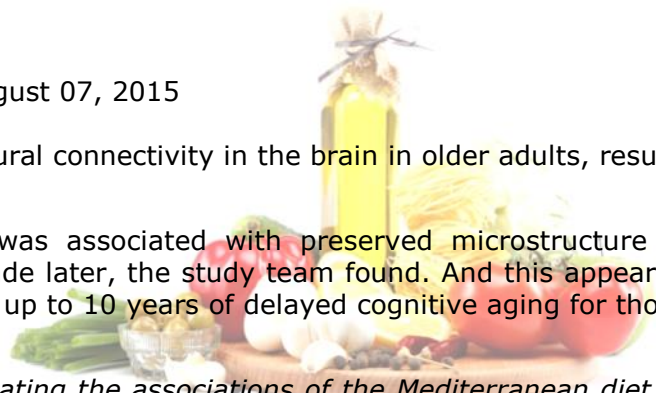
Greater adherence to the Mediterranean diet was associated with preserved microstructure in extensive areas of the white matter up to a decade later, the study team found. And this appeared to be related to strong cognitive benefit, equal to up to 10 years of delayed cognitive aging for those with the greatest adherence, they say.

"This is to our knowledge the first study investigating the associations of the Mediterranean diet to brain structure in humans, focusing not only on grey matter volume but also on white matter architecture (a more novel marker of brain health)", Cecilia Samieri, PhD, from University of Bordeaux, France, told Medscape Medical News.

"The findings give mechanistic clues on the link between the Mediterranean diet and lower cognitive aging which have been suggested in previous research", she said.

The study was [published online](#) July 16 in *Alzheimer's & Dementia*.

Check [this link](#) for the 10 Commandments of "The Real Mediterranean Diet". 



How To Know Whether To Believe A Health Study

By Austin Frakt

Source: New York Times
– 17 August 2015



Picture – Pete Ryan

Every day, new health care research findings are reported. Many of them suggest that if we do something — drink more coffee, take this drug, get that surgery or put in this policy — we will have better (or worse) health, or longer (or shorter) lives.

And every time you read such news, you are undoubtedly left asking: Should I believe this? Often the answer is no, but we

may not know how to distinguish the research duds from the results we should heed.

Unfortunately, there's no substitute for careful examination of studies by experts. Yet, if you're not an expert, you can do a few simple things to become a more savvy consumer of research. First, if the study examined the effects of a therapy only on animals or in a test tube, we have very limited insight into how it will actually work in humans. You should take any claims about effects on people with more than a grain of salt. Next, for studies involving humans, ask yourself: What method did the researchers use? How similar am I to the people it examined?

Sure, [there are many other important questions to ask about a study](#) — for instance, did it examine harms as well as benefits? But just assessing the

basis for what researchers call "causal claims" — X leads to or causes Y — and how similar you are to study subjects will go a long way toward unlocking its credibility and relevance to you.

Let's look closer at how to find answers. (If the answers are not in news media reports, which they should be, you'll have to chase down the study — and admittedly that's not easy. Many are not available without cost on the web.)

It's instructive to consider an ideal, but impossible, study. An ideal study of a drug would make two identical copies of you, both of which experience exactly the same thing for all time, with one exception: Only one copy of you gets the drug. Comparing what happens to the two yous would tell us the causal consequences of that drug for you.

Continue reading the full article [here](#).

Man Has Polio Virus Living In Gut For 30 Years

by [Rachael Rettner](#), Senior Writer

Source: Live Science - 27 August 2015

A man in the United Kingdom experienced a very rare complication of the polio vaccine he received in childhood — he never cleared the virus from his body. As a result, the virus has been circulating in his gut for nearly 30 years, and is still being excreted in his stool today, according to a new report of the case.

Although it was known that some people could shed the virus from their bodies for long periods, the new case is by far the longest that the virus has stuck around in a person, the researchers said.

Cases like these could potentially spread polio, and interfere with efforts to [eradicate the virus](#), the researchers said.

The new findings "raise questions about how the population may best be protected from" these particular polio viruses, the researchers said. [[7 Devastating Infectious Diseases](#)]

Poliovirus has been eradicated nearly everywhere except for a few countries, including Afghanistan and Pakistan, although the virus has seen a re-emergence in countries such as Syria in recent years.

There are two types of [polio vaccine](#) used to prevent the disease: one type contains dead strains of the virus and must be injected, whereas the other type, the oral polio vaccine, contains a live but weakened virus.

The oral vaccine has a few advantages, including that it is easy to administer, and can more quickly stop the virus from replicating in a person's gut, if that person is exposed to the virus. However, there is a very small risk that the vaccine can cause the illness itself.

Man Has Polio Virus Living In Gut For 30 Years (cont'd)

In addition, there is risk that the virus can linger in the gut of people who are given the oral vaccine. The vaccine works by prompting immunity to develop in the gut because the weakened virus briefly replicates there. People usually clear the virus from their gut in six to eight weeks after vaccination, but in very rare cases, people with [immune system](#) disorders cannot clear the virus, and it continues to replicate in their gut.

That's what happened to the patient in the new report, a 29-year-old white man who was given the vaccine as an infant. (The man has never developed the disease itself.)

The researchers analyzed more than 100 stool samples from the patient, which were collected between 1995 and 2015. They found high levels of the polio virus in the samples. What's more, tests showed that the polio viruses in the patient's gut were different from those in the vaccine, meaning that mutations had developed in the virus over time.

The viruses in the patient's gut were able to cause paralysis in a mouse model, suggesting that these strains are very virulent. However, tests with human blood from people who were vaccinated against polio showed that the antibodies in the people's blood were able to kill the viruses from the patient.

"These results are reassuring in that they indicate that vaccinated humans are well protected against infection" with these virus strains, the researchers said.

But the researchers noted that they used blood from people who had been vaccinated with the oral vaccine, and it's not clear if people vaccinated solely with the inactivated vaccine would show the same level of protection. In the U.S., children have been given the inactivated vaccine since the year 2000; prior to that, the oral vaccine was used.

There have been only 73 documented cases of people with immune problems who had the [polio virus](#) replicate in their intestines for prolonged periods. But it's possible that some cases were missed — strains of polio that differ from those in the vaccine have been found in sewage samples from Slovakia, Finland, Estonia and Israel, the researchers said. These findings suggest that *"an unknown number of these chronic excreters exist elsewhere,"* the researchers said.

Surveillance of sewage and stool samples should be done to search for polio strains, the researchers said. In addition, there is a need to develop antiviral treatments for patients like the one in the current study, because there is currently no effective way to stop the replication of the polio virus.

"These measures are needed to be able to identify and manage the possible risks of [divergent] strains spreading and causing disease in patients and the general population," the researchers said. Finally, new polio vaccines may be needed to fully eradicate the illness, they said.

Full article [here](#). 🌐

Study Finds Injected Polio Vaccine Safe

Source: [CIDRAP](#)—17 August 2-15

Thirteen years of US safety data on the inactivated poliovirus vaccine (IPV, or polio shot) show that it is not associated with major side effects, a study yesterday in *The Lancet Infectious Diseases* noted.

Researchers from the Centers for Disease Control and Prevention (CIDRAP), the Food and Drug Administration, and Emory University in Atlanta studied data on 41,792 adverse events submitted to the US Vaccine Adverse Event Reporting System (VAERS) from Jan 1, 2000, through Dec 31, 2012.

Given that more than 250 million IPV doses were administered during that period, the rate of adverse events was about 0.02%. Also, stand-

alone IPV administration was recorded for only 0.5% of the events, as most doses were given in combination with other childhood vaccines.

Among the adverse events reported, 34,880 (88%) were for non-serious events, 3,905 (10%) were for non-fatal serious events, and 783 (2%) were death reports. Almost all deaths (96%) were in children 1 year old or younger, and 52% had sudden infant death syndrome as the reported cause of death. These rates are similar as data on the oral polio vaccine, the authors noted.

The researchers concluded, *"No new or unexpected vaccine safety problems were identified."* An accompanying commentary called the results *"good news."*

Aug 16 *Lancet Infect Dis* [study](#) / [commentary](#) 🌐

One Year Since Africa Has Had Any New Polio Cases

By [Eleanor Goldberg](#), *Impact Editor*

Source: [The Huffington Post](#) - 11 August 2015

Tuesday marks one year since Africa has had any new polio cases, a monumental step toward the continent being completely rid of the disease.

Since a case was recorded in [Somalia a year ago](#), there has been no evidence of any new incidents, an accomplishment advocates attribute to a collaborative, multi-tiered effort, UNICEF noted. Volunteers, religious leaders, health workers and government agencies have banded together to bring vaccines to rural areas and to dispel myths associated with getting the shots.

Polio mainly affects children under 5 years and can lead to irreversible paralysis and death in some cases when breathing becomes compromised, according to the World Health Organization.

The disease has never been stopped in Afghanistan, Pakistan or Nigeria, according to NPR.

While Somalia has had its hopeful moments over the years, the disease hasn't yet been completely wiped out.

After three polio-free years, the disease resurfaced in 2005 in Somalia with 185 confirmed cases, and smaller outbreaks the following three years, according to UNICEF.

In 2008 there was an outbreak in Jonglei State, close to the border with Ethiopia.

"It is hard to describe the isolation of this place - an area of marshes, vast cotton-soil

plains that become impassable after rains, and an area that has long been plagued by insecurity", Peter Crowley, head of UNICEF's polio unit, wrote in a blog post.

Yet, despite such challenges, the outbreak was contained and the area has not experienced a new case since.

To effectively protect Somalians from the disease, advocates have looked to religious leaders to urge their congregants to get vaccinated.

Some parents resisted getting their children vaccinated, saying that it conflicted with their religious beliefs.

But in 2007, the country saw a major breakthrough when 40 religious leaders from North East Somalia declared their support for polio prevention efforts.

"We agree with the conclusions of the doctors", Hagi Ali Ahmed, a sheikh from Puntland, said in a statement. *"Rumors were wrong. Religious leaders must create awareness in all mosques and among the community"*.

Nigeria is also on its way to becoming polio-free. July marked a year since the country had recorded any new polio cases, NPR reported. There, health workers also contended with deleterious pushback.

Vaccinators were periodically attacked and killed because religious leaders believed their work to be part of a Western plot to sterilize Muslim children.



While health workers have made extraordinary gains in assuaging suspicions in Nigeria and Somalia, religious leaders have recently grown wary of vaccine campaigns in Kenya.

The country's Conference of Catholic Bishops recently [boycotted WHO's polio vaccine campaign](#) until it can verify that there is no presence of oestrogen in the shots, NPR reported. Dr Wahome Ngare of the Kenyan Catholic Doctor's Association accused the organization of introducing female hormone that could sterilize children.

Though health workers and advocates are celebrating Somalia's latest polio milestone, they're not at ease just yet. It will take another two years before the country can officially declare itself polio-free.

"While today's milestone is extraordinary, it is not an endpoint", Crowley said. *"Nigeria and the many other African countries that remain at risk for polio must maintain high-quality surveillance, work ever-harder to improve the quality of vaccination campaigns and act decisively, should further outbreaks occur"*. 🌍

Why Are Catholic Bishops Boycotting Polio Vaccines in Kenya?

By [Lizbeth Paulat](#)

Source: [Care2.com](#) – 14 August 2015

International health organizations reacted in shock last week after the Conference of Catholic Bishops in Kenya [announced a boycott of polio vaccines](#). This comes on the heels of Africa's first year without a single polio case. The bishops have said they want to carry out more independent testing on the vaccines to make sure they don't contain estrogen derivatives, which they claim are being used to sterilize women and children.

It's a claim that sounds like science fiction, but this issue has been brewing for some time. It started last year when a tetanus vaccination was accused of sterilizing around 500,000 women in Kenya. The Catholic Doctors Association claims that they picked six random samples of the tetanus vaccine from around Kenya and sent it to South Africa for independent testing. They said that when results came back, [30 percent of the vials contained an anti-pregnancy additive](#).

Doctors with the WHO and UNICEF came out insisting the vaccine was safe and government officials backed them up, with the Minister of Health famously saying he'd encourage his own daughter to take the vaccination. Yet for many Kenyans a routine vaccination suddenly looked like a harrowing choice.

There is a mass distrust of vaccinations and western medicine both in Kenya and around different parts of Africa. Unlike U.S. fears about vaccinations (which have all been thoroughly debunked) a sheer mass of unethical medical trials across the African continent have only stoked these flames of fear.

Many on the continent feel that the long history of unethical medical trials and forced sterilizations points to proof of continued conspiracies. Forced sterilization and contraception programs existed in pre-Zimbabwe Rhodesia, Namibia and South Africa. And in case you think this was likely all during the colonial era, it's worth noting that up until 1989 chemical castration and forced sexual reassignment was taking place in South Africa.

And these unethical issues remain until the present day. In 2004 and 2005, women in Cameroon were infected with HIV during a study

on an anti-transmission medication. In 2003, a Ugandan trial for nevirapine, designed to reduce HIV transmission from mother to child, failed to report 14 deaths. And a mid-90s study on an anti-meningitis medication in Nigeria was administered without parental consent and resulted in nerve damage, brain damage and death for a number of children.

This is why when Ebola came to light, and western medical institutions started arriving, many West Africans were suspicious. Many in the U.S. criticized this backlash as silly Africans not understanding what was best for them. Yet what many in the West failed to grasp was the long history of abuse Africans have dealt with at the hands of the scientific community.

The drop in deadly diseases across the African continent is truly commendable and due largely in part to these health organizations and grassroots community advocacy. However, these fears come from very real issues that have plagued societies around Africa since the colonial era.

Because of this, international organizations such as the WHO and UNICEF, should not breezily dismiss these possibilities. Rather they should engage with local communities about their issues. Complete transparency in what is contained in the drug, complete transparency in what the parents can expect and informed consent are all imperative for earning back the trust of these long-exploited communities.

Read more [here](#). 🌍



Pakistan Hopeful of Eradicating Polio By Next Year

Source: [The Health Site](#) – 8 August 2015

India has been successful in eradicating polio but Pakistan is still striving to do so. But now the country plans to do so by 2016. A Pakistani official has said that a National Routine Immunisation Plan is in the pipeline aimed at permanently eradicating the disease from the country, the media reported on Saturday.

According to official figures, Pakistan had 306 polio cases in 2014, the highest in 14 years and the majority of them were in the Federally Administered Tribal Area (FATA) and Khyber Pakhtunkhwa. So far this year, 24 cases have been reported countrywide. Pakistan, Afghanistan and Nigeria are the only countries in the world which are still battling to eradicate polio.

Minister of State for National Health Services, Saira Afzal Tarar said the comprehensive immunisation plan would be aimed at eradicating

the virus by next year. *"The prime minister has formed a Routine Immunisation Committee of the federal cabinet, comprising three members, including me and the defence minister, to prepare the strategy to permanently eradicate polio from the country,"* she said. She said despite the fact that anti-polio campaigns faced problems in areas where the law and order situation had worsened, a nationwide drive would be launched soon.

She added that 6,000 community health volunteers would be engaged to improve immunisation coverage in low coverage union councils by distributing vaccination cards, giving polio drops to eligible children and advocating with the community on routine immunisation. Attempts to eradicate the disease have been badly hit by militant attacks on immunisation teams since December 2012. Militants claim the polio vaccination drive is a front for espionage or a conspiracy to sterilise Muslims. 🇵🇰

Supermodel Fighting For Polio-Free World



Click the image to link to the video

By Esha Chhabra

Source: [Takepart](#)—17 July 2015

Rotary International ambassador Isabeli Fontana discusses the organization's campaign to eradicate polio.

Isabeli Fontana's famous face has graced national campaigns ranging from Victoria's Secret to L'Oréal—there's a reason she's on *Forbes'* "World's Top-Earning Models" list—but she's also the face of the cause she says matters to her the most: polio vaccination.

The supermodel was tapped by Rotary International two years ago to become an

ambassador for the Global Polio Eradication Initiative and travelled to India this past spring to see the program in action. Rotary also held its annual convention in São Paulo last month, where Fontana was a keynote speaker on the issue. For Fontana, her goal as ambassador is to get more deeply involved in the campaign and use her family as an example for others to follow.

"I do more than just lend my image and voice," she tells me when we meet for dinner in Delhi one night; she had spent the day helping vaccinate kids and visiting polio patients at St. Stephen's Hospital. *"I took my youngest son to get the oral polio vaccine drops directly from the Brazilian minister of health,"* she says.

So, Why Should You Care? India became [polio-free](#) in 2014 after battling the disease for nearly 30 years, but the campaign continues in order to ensure that no new cases emerge. India's neighbours Pakistan and Afghanistan are the two remaining polio-endemic nations in the world. Nigeria, a third nation on the list, is poised to complete one year without any new cases and will be officially listed as polio-free on July 24. India has been used as a reference point—an example from which to draw lessons—for these other nations that are still battling the virus.

Read the full interview [here](#). 🇮🇳

Polio This Week

Source: [Polio Global Eradication Initiative](#)—as of Wednesday 26 August 2015

Wild Poliovirus Type 1 and Circulating Vaccine-Derived Poliovirus Cases

Total cases	Year-to-date 2015		Year-to-date 2014		Total in 2014	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Globally	37	10	145	31	359	55
-in endemic countries	37	1	128	31	340	52
-in non-endemic countries	0	9	17	0	19	3

Case Breakdown by Country

Countries	Year-to-date 2015		Year-to-date 2014		Total in 2014		Onset of paralysis of most recent case	
	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV	WPV	cVDPV
Pakistan	29	0	115	16	306	22	30-Jun-15	13-Dec-14
Afghanistan	8	0	8	0	28	0	17-Jul-15	N/A
Nigeria	0	1	5	15	6	30	24-Jul-14	16-May-15
Somalia	0	0	4	0	5	0	11-Aug-14	N/A
Equatorial Guinea	0	0	4	0	5	0	03-May-14	N/A
Iraq	0	0	2	0	2	0	07-Apr-14	N/A
Cameroon	0	0	5	0	5	0	09-Jul-14	N/A
Syrian Arab	0	0	1	0	1	0	21-Jan-14	N/A
Ethiopia	0	0	1	0	1	0	05-Jan-14	N/A
South Sudan	0	0	0	0	0	2	N/A	12-Sep-14
Madagascar	0	9	0	0	0	1	N/A	07-Jul-15

[Circulating vaccine-derived poliovirus](#) cVDPV: Madagascar is cVDPV1, all others cVDPV2. NA: onset of paralysis in most recent case is prior to 2014. cVDPV is associated with ≥ 2 AFP cases or non-household contacts. VDPV2 cases with ≥ 6 (≥ 10 for type1) nucleotides difference from Sabin in VP1 are reported here.

This week, Pakistan will become the second polio-endemic country to introduce the inactivated polio vaccine (IPV) into its routine immunization system. More than half the global birth cohort is now receiving at least one dose of IPV through routine immunization systems as a result of the biggest globally synchronized vaccine introduction in history.