



Polio Oz News

March 2017 – Autumn Edition

Polio Australia Salutes A Remarkable Life

Is Florence Jean Barber "Australia's Longest Living Polio Survivor" at 102 years of age? This was the question Florence's nephew recently contacted Polio Australia to find out. And, to be quite honest, we don't really know . . . However, Polio Australia did feel that this milestone certainly warranted recognition by way of a plaque.

Polio Australia's Board Member and volunteer National Communications Coordinator, Gary Newton (who featured in the Summer 2016 edition of *Polio Oz News*), just happens to live in the same area as Florence and her nephew. So, on Monday the 13th of February, Gary and Winnie Teo, Coordinator of the Geelong Polio Support Group, paid Florence a visit on behalf of Polio Australia, to present her with a plaque acknowledging Florence Jean Barber as "Australia's Longest Living Polio Survivor". Winnie also gave Florence a lovely flower arrangement from the Geelong Polio Support Group.

There may be a longer-lived polio survivor somewhere in Australia who we haven't come across yet. However, we still think the remarkable Florence Jean Barber deserves her 15 minutes of fame! Read more about Florence in the following story.

- Ed ●

The Story Of Florence Jean Barber

As told by family member, Helen Barber

Florence Jean Barber was born in Gilgandra, New South Wales, on the 4th of October, 1914, but has lived most of her life in the Werribee and Geelong areas. Her father and mother had a farm in Werribee, which was very different back then.

Florence has lived a very full life. When she contracted polio in 1917 in Geelong, her father made her a special tricycle to get around, which she operated with her left hand. Perhaps it was the early memory of her tricycle that later inspired her to learn to drive, which was a terrific thing for her because that was how she gained her independence.

Although driving required the use of her feet to some degree, a lot of it was modified for hand operation. We used to worry because she would manually lift her leg with her hands to change between the accelerator and the brake, which meant there was always a delayed reaction. However, driving did provide her with a lot of freedom.

In raising Florence, I think her parents would have been quite protective of her, but she has an independent spirit. When she eventually got the car, I imagine her mother would have felt quite anxious about letting Florence go. However, it was a real turning point when she was able to take her mother out for a drive.



L-R: Gary Newton, Florence Barber,
and Winnie Teo

(cont'd P3)

Polio Australia

Representing polio survivors
throughout Australia

Suite 605A, 89 High Street
Kew Victoria 3101
PO Box 500
Kew East Victoria 3102
Phone: +61 3 9016 7678
E-mail: office@polioaustralia.org.au
Websites: www.polioaustralia.org.au
www.poliohealth.org.au
www.australianpolioregister.org.au

Contacts

President—John Tierney OAM
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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President's Report

Dr John Tierney OAM
President

As you all would be aware, for the last eight years Polio Australia has been lobbying the federal parliament for recognition and support for Australia's 400,000 polio survivors. We have had stunning success in raising the profile of polio survivors, especially through *Walk with Me* and *We're Still Here* campaigns.

On the other hand, our campaign to access federal funding has not been successful. We did however, almost get over the line in 2014, but fell at the last hurdle when there was a change in health minister. Helping us at that time were our six cross party *Parliamentary Patrons*.

One of the great things about lobbying is that if you stick with it long enough, the cards sometimes just fall your way. We now have an excellent hand of cards, because through the political promotion system over eight years, we now have two of our parliamentary patrons in the box seat. The Hon Greg Hunt MP (Liberal, Victoria) is now the Cabinet Minister for Health and the Hon Catherine King MP (ALP, Victoria) is now the Shadow Minister for Health. So in our corner we now have the current and the next health minister! How can we miss?

Both MP's have met with us many times, read our material and come to our functions in Parliament House over many years. All we now need to do is imbue them with the **will** to release health resources to support the very obvious needs of Australia's polio survivors. To this end, our lobbying team has drawn up a revised proposal, which we intend to take to Canberra in a few months time.

Please wish us luck.

In the last edition of *Polio Oz News*, I profiled Michael Powell, the new Queensland representative on the Board of Polio Australia and the CEO of Spinal Life Australia. SLA is Brisbane based and auspices the polio survivors support groups in Queensland. At our 2016 AGM, Michael signaled that SLA, under his leadership, is keen to develop more support mechanisms for their post-polio membership and to further develop the polio support network across Queensland. Part of this change could also be the provision of more support for the backup work of Polio Australia.

Both Michael and I reported on the meeting outcomes to the most recent Board meeting of the Polio Australia in February. We were given support for further discussions on what measures might be possible to co-operatively develop a better support system for polio survivors. This would be initially in Queensland, with the possibility of additional resource support being provided to Polio Australia.

Given Polio Australia's mixed success with support from government and community organisations, this developing partnership with Spinal Life Australia is indeed a most exciting development. In each future edition of *Polio Oz News*, I will continue to report progress. 🌟

John



It's a new season
An opportunity to do
Something new
Something bold
Something beautiful

Anon

From the Editor



Mary-ann Liethof
Editor

It's a brand new year and I'm sitting in my bright new office (same building) looking out of my window at the lovely sunny view, and thinking how lucky I am to be alive. I haven't had an external window for the six years that I've operated Polio Australia, in addition to three years in my previous job. It's amazing how natural light can improve your outlook in more ways than one! That, and the

fact that I'm about to go on a three week holiday — which is why *Polio Oz News* is coming to you two weeks early!

As we hurtle through another year at full tilt, do you ever wonder what life will be like in another decade, or two, or three, at the age of 102? Hopefully, if we are one of those rare people who even reach that milestone, we will feel as fulfilled as Florence (p1). Maybe it's all in the gardening and taking time to smell those roses . . .

If you are finding that pain is a constant, albeit unwanted, companion in your life, perhaps you would consider sharing your coping strategies by filling out an online survey (p4). This is for a UTS research project which may just assist other polio survivors develop strategies to better manage their condition.

I have often had polio survivors tell me that they have trouble convincing family, friends, and even health professionals that they are actually suffering with the Late Effects of Polio because they 'look OK'. If this is your experience, you will be interested to read about 'Invisible Disabilities' (p5) and how it impacts on 'OK-looking' people who need to use a disability car

The Story Of Florence Jean Barber (cont'd from P1)

Florence used to work at Bright & Hitchcock, a department store operating from the same site from 1855 to 1979 in Geelong. She was employed as a seamstress and she would alter clothes for people; fixing hems, modifying fittings, and so on.

Florence has been a keen gardener all her life. I remember visiting her in Newtown where I'd see her sitting on the ground, tending her garden bed. Florence was always proud of her garden, growing and even selling lovely chrysanthemums and other flowers. She also loved cooking and used to do a lot of baking.

Polio affects Florence's legs and she wore a calliper on her left leg most of her life. She lived on her own until she was 95, when she contracted a lung infection and was admitted to a respite facility. After that, health workers said

parking space.

Those of you who are looking forward to reading about Gary Newton and his team's exploits in India (*Polio Oz News — Summer 2016 Edition, p1*) will now need to wait a little longer. As we all know, sometimes even the best laid plans can go awry. However, a little more time to ensure everyone is able to fully participate is really all for the best. Read Gary's India Project update on p9.

If you live in Sydney or Brisbane and are in the market for a new mobility device, car modification, or any kind of assistive technology, you might like to visit the Independent Living Expo (p9) in your state. It's free and showcases all the latest aids and equipment.

However, before purchasing that wonderful new 'thing', you should first read all about the free new ACCC resource (p13), which outlines the rights and obligations of consumers and businesses in the disability sector.

The final page of this edition is an *Expression of Interest* form for the 2017 Polio Health and Wellness Retreat being held on Queensland's Sunshine Coast from Thursday 26th to Sunday 29th of October. It's still early days, but if you think you might be interested in participating in this year's Retreat, please complete the form and send it in to be kept up-to-date.

These articles, and more, including polio memories, and polio eradication, can be found in the following pages.

Finally, we're still waiting to launch the www.postpolioconference.org.au website, but it shouldn't be too much longer . . . Stay tuned! 🌟

Mary-ann

she couldn't go home because she could no longer put her calliper back on and had no way of standing up at all.

Since then, Florence has lived in an aged care home. She is no longer able to use her legs, so relies on a wheelchair and being transferred by staff. However, Florence is a long-time member of the Geelong Polio Support Group, and whilst she no longer attends meetings, she still looks forward to receiving their newsletters each month! 🌟



Post-Polio Syndrome and Pain Coping Strategies

The theme of the May 2016 Polio NSW Seminar was "*Managing Pain*". The speakers presented various options available to manage pain, improve functioning and quality of life, including strategies for self-management.

One of the speakers at the seminar, Dr Toby Newton-John, asked if members would be interested in taking part in a research project exploring Post-Polio Syndrome and pain coping strategies. They were asked to indicate their interest in participating by sending their name and contact details to him by email or mail.

Shortly after, it was decided to broaden the

reach of the survey to include as many polio survivors as possible by making the survey known to all polio organisations in all states in Australia. Subsequently, Polio Australia was asked to promote the project through *Polio Oz News*.

In October 2016, Dr Toby advised us that Kristine Koh, a Masters student, was preparing the survey for approval by the Ethics Board and that Kristine would be conducting the study.

The research survey has now been launched and a 'pilot test' on the survey questions was trialled.

The Research Project is detailed below. ●

Chronic Pain and PPS Research Project

Who?

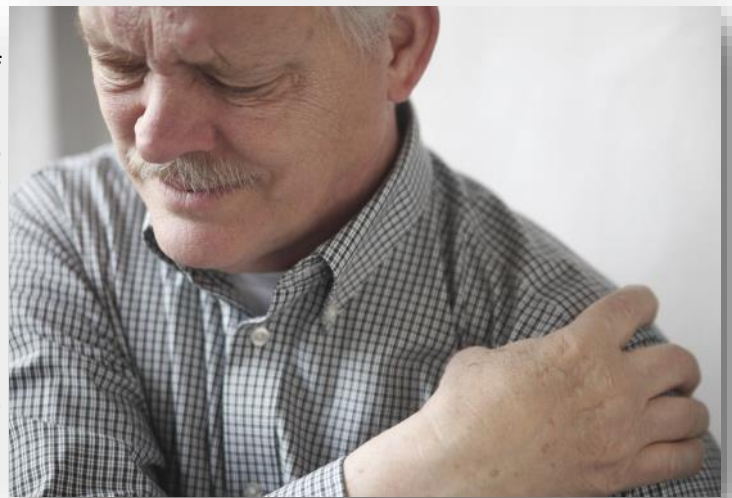
University of Technology Sydney (UTS) Master of Clinical Psychology student, Kristine Koh, and supervisor Dr Toby Newton-John, are conducting a research project and would like to invite members with Post-Polio Syndrome (PPS) who are experiencing chronic pain to take part. They are hoping to recruit between 100 and 200 participants.

What?

This research is investigating the pain experiences of people with PPS and seeks to identify the different coping strategies used to manage chronic pain in daily life. It is also hoped that this research can shed light on how the use of different coping strategies affects the experience of chronic pain and PPS. It is an important area that has not been adequately investigated, and this research project will extend the scientific study of PPS. We hope to use the information in order to significantly improve quality of life, for people with PPS and chronic pain.

How?

This study involves completing a survey online at your convenience. The survey will take 25 to 35 minutes your time, but you have to complete it over one week. To begin the survey, click on or enter the link below into your web browser: <http://tinyurl.com/ChronicPain-PostPolioSyndrome>



This survey will be available for completion from 17th February 2017 to 1st of July 2017.

Thank you for interest and participation in this study.

If you have any questions, please email:

Kristine at weilingkristine.koh@student.uts.edu.au, or
Dr Toby Newton-John at toby.newton-john@uts.edu.au

Invisible Disabilities

People with Invisible Disabilities Face Harassment in Car Parks

Source: Blue Badge Insurance

Have you ever seen someone who looks perfectly healthy using an accessible parking space? Did you assume that they were cheating the system? Did you know that many disabilities are invisible and have no obvious external signs?

We've all seen the international symbol for disability printed on every accessible parking space. It's a little blue stick figure in a wheelchair, showing everyone that a space is reserved for people with disabilities. The only problem is, not everyone with a disability looks like that stick figure. Very few of us are blue, not all of us use wheelchairs and many of us don't look disabled at all.

People with invisible disabilities often face harassment and discrimination from people who assume that they are using accessible parking illegally. This harassment can cause serious distress to people living with debilitating illness.

What is an Invisible Disability?

An invisible disability, as the name suggests, is a disability that cannot be easily seen by others. Although they may appear able bodied at first glance, people with invisible disabilities often live with symptoms like pain, fatigue, balance problems, cognitive or mental dysfunction and vision and hearing impairments. Some invisible disabilities fluctuate, meaning that someone may be able to walk one day, but require a wheelchair the next. People with invisible disabilities often experience discrimination from both able bodied people, who may not believe that they are disabled, and from other disabled people who may envy their ability to 'pass' as able bodied.

People with invisible disabilities can require Disability Parking Permits for many reasons. Accessible spaces are located close to facilities, this allows shortened walking times and access to hired mobility scooters and wheelchairs. It avoids exposure to heat, cold, and exhaust fumes and allows people to use their limited energy on their chosen activity, not on getting to and from the car. The close proximity of accessible parking also limits exposure to hazards such as traffic and uneven footpaths. Accessible parking spaces are also wider than average, allowing extra room for people with limited or unpredictable movement, or who need assistance to get in and out of the car.

Discrimination and Abuse

Sadly, people with invisible disabilities often face harassment from people who assume that they



are cheating the system. In January 2016, Tasmanian Steven Maksimovic reported being harassed six times over a three-month period for using his Disability Parking Permit in and around Hobart. Some of these confrontations caused distress to Maksimovic's six-year-old son who witnessed the events.

In November 2015 Victorian woman Justine Van Den Borne, who lives with Multiple Sclerosis (MS) caused a storm on social media defending her right to a use accessible parking after she found a nasty note taped to her windscreen saying "Did you forget your wheelchair???". Justine responded to the anonymous note on Facebook, saying "On the day you saw me I was having a good day. I was walking with my daughter unaided having a nice day. Thank you for ruining that. You made me feel like people were looking at me, the exact way I feel when I can't walk properly. I am sick of people like yourself abusing me on my good days for using a facility I am entitled to".

Although these are extreme examples, people with invisible disabilities often face more subtle forms of discrimination when parking. These might include being stared at, or hearing people make rude comments about them under their breath. Discrimination can have very real effects on the lives of people with invisible disabilities, making them feel self-conscious, unsafe or guilty for using the facilities that they are entitled to. These feelings can in turn lead to an unwillingness to go out, increased social isolation, anxiety and depression.

The Blue Badge Insurance Guide to Common Invisible Disabilities

There are literally thousands of conditions that may cause invisible disabilities. Here are just a few:

Invisible Disabilities *(cont'd from p5)*

- Back Injuries
- Brain Injuries
- Chronic Illnesses
- Heart Conditions
- Muscular Disorders
- Neurological Disorders
- Seizure Disorders
- Recent Surgery

Who Can Park in an Accessible Space?

Australia has strict regulations outlining who can hold a Disability Parking Permit. Permit holders have all completed detailed forms that have been authorised by their doctors and approved by their local council. Displaying a Disability Parking Permit is proof that a person is eligible to use an accessible space, no matter what they look like. Check the following website for details: www.bluebadgeinsurance.com.au/new-national-disability-parking-permits-designed-help-reduce-fraud/

People without disabilities are also legally allowed to park in accessible parking spaces if they are stopping to pick up someone who has a disability. In this case, they must display the Disability Parking Permit of the person with a disability. Remember, not everyone who is eligible to use accessible parking is obviously disabled. Anyone displaying a permit has already proven their eligibility and demanding further proof is harassment.

Staying Safe while Parking with an Invisible Disability

Do you have an invisible disability? Have you ever been harassed or felt unsafe while parking? There are a few things you can do to protect yourself.

If someone confronts you, do not engage or argue with them. You do not have to tell them anything about your disability; that is private information between you and your doctor. You may wish to make a short comment like "I have a legal permit".

If you are followed or harassed, make your way inside to the nearest building. Explain your situation to a staff member and, if necessary, ask them to call security or the police. If someone leaves a nasty note on your car, be sure to take a photo of it to provide proof of what happened.

Finally, if you repeatedly face problems in a specific area, you may like to raise awareness of the issue by contacting your local newspaper. Many people misguidedly think they are helping disabled people by calling out parking 'cheats' and may reconsider their actions once they realise that invisible disabilities exist.

Are you a person with an invisible disability? Share your accessible parking story with Blue Badge Insurance at:

www.bluebadgeinsurance.com.au/my-story/

As Australia's first independence and mobility insurance specialists, **Blue Badge Insurance** offers a variety of products for people with disabilities and restricted mobility including mobility scooter insurance, wheelchair insurance, home and contents insurance and car insurance.

Based on over 30 years' experience in the UK, Blue Badge take a different view from most insurers by discriminating positively for the hundreds of thousands of Australians who use a disability parking permit.

Their most innovative product is the Comprehensive Car Insurance policy, which provides discounts exclusively for disability parking permit users. They insure anyone who holds a permanent disability parking permit, including people who have converted their car to accommodate a disability.

Polio Australia is proud to have recently partnered with Blue Badge Insurance to offer Polio Oz News readers a limited time offer whereby they will donate \$10 to Polio Australia's 2017 Polio Health and Wellness Retreat for every member who contacts them for an obligation free car insurance quote before 30 April 2017.

All you need to do is call the Blue Badge Insurance Customer Service Team on 1300 304 802 and mention **POL001** to activate this donation offer. Email quotes are also available at: info@bluebadge.com.au



QUOTE AND DONATE

For a limited time, Blue Badge will donate \$10 to Polio Australia's annual health and wellness retreat for every member who calls them for an obligation free car insurance quote*. Mention POL001 to claim this offer.

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INSURANCE
AUSTRALIA



Do ordinary insurers care where you park? **We do!**

Discounted car insurance for disability parking permit users

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*This Blue Badge Insurance offer is limited to one insurance quote per customer between 1 February and 30 April 2017. The quote documentation must be mailed or emailed to the customer. This offer is not available to be combined with any other promotions that Blue Badge Insurance may offer. To take advantage of the offer you must tell us the quote offer code "PARK001". *Discounts for the Blue Badge Insurance Comprehensive Motor Vehicle Insurance will be applied to the base vehicle rates subject to the customer holding a permanent Disability Parking Permit and/or the vehicle has been converted for use by a driver or passengers that have a disability. The discounts do not apply to the Blue Badge Roadside Assistance Optional Benefit. Underwriting criteria will be applied to the consideration of the risk. Additional excesses will apply to drivers under 25 or those drivers who have held a full Australian drivers licence for less than 2 years. This offer may be withdrawn at any time. Consider the PDS at www.BlueBadgeInsurance.com.au to decide if the product is right for you. Blue Badge Insurance Australia Pty Ltd ABN 59 162 783 306 (A.R. No. 438547) is an Authorised Representative of Insurance Logic. Pty Ltd ABN 44 002 859 252 (AFS Licence No 237633) and The Hollard Insurance Company Pty Ltd ABN 78 090 584 473 (AFS Licence No 241436).

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 November to 31 December 2016.

Hall of Fame

| Name | Donation |
|-------------------------|------------|
| Anonymous | \$5,000.00 |
| Dr John and Pam Tierney | \$1,000.00 |
| Total—\$6,000.00 | |

General Donations

| Names | | | |
|-----------------------|-------------|-----------------|----------------|
| Jill Burn | Liz Telford | Russell Tillott | Gillian Thomas |
| Total—\$740.00 | | | |

Brisbane (Sep) and ACT (Nov) Walk With Me Activities

| State | Total donations for Nov/Dec |
|------------------------|-------------------------------|
| ACT | \$4,717.74 |
| NSW | \$3,042.62 (50% to Polio NSW) |
| Post-Polio Victoria | \$1,051.45 (50% to PNV) |
| QLD | \$3,623.49 |
| SA | \$20.00 |
| WA | \$1,473.88 |
| General | \$1,315.00 |
| Total—15,243.88 | |

Bribie Island Fashion Fundraiser

Processed through the Rotary Club of Bribie Island

Total—\$2,632.00



Above: Bribie Island Fashion Fundraiser



Above: Walk With Me Canberra

Left: Walk With Me Brisbane

Independent Living Expos

ATSA
INDEPENDENT
LIVING
EXPO

10-11 May 2017
Sydney Showground,
Sydney Olympic Park

24 May 2017
Royal International
Convention Centre, Brisbane



**REGISTER
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The ATSA Independent Living Expo will have over 100 exhibitors displaying a wide range of products and services in assistive technology, mobility solutions, pressure care, employment support, accessible recreation/holiday ideas, modified motor vehicles and a lot more.

ATSA Independent Living Expo is open to visitors of all ages, including those with a disability, seniors and their families, friends and carers.

A key feature of the Expo is the FREE Conference Program – run in rooms conveniently located next to the exhibition floor.

Admission is free to therapists, the general public, end users and ATSA members.

Visit the website for more information:
www.atsaindependentlivingexpo.com.au

Gary's Polio Project to India – Update

"Gary's Indian Summer" was a feature in the Summer 2016 edition of *Polio Oz News*. Gary Newton and his team had planned to head off to India in January 2017. However, due to some major medical problems with one of the members, Gary's team are forced to postpone the trip to India until January 2018, the date of the next available winter (in Delhi) National Immunisation Day.

This is a really good thing for two important reasons:

1. It gives those who are unwell time to recover from their illness; and
2. It also gives the group more time to raise much needed funds to reach their target of \$50,000, which comprises \$25,000 for travel expenses to get the group's polio survivors and carers to India for roughly 12 days, AND \$25,000 to go as a donation to help eradicate polio forever, keep India polio-free, and support polio survivors both here and in India.

If you haven't checked out the Facebook page yet for all that's going on, go to: facebook.com/GarysPolioProject



Une baguette.
S'il vous plait,
mate.



Fold, Pack, Travel

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WH20495/PO

Polio Then And Now

The story of a crippling disease on the verge of worldwide eradication

By Katie Forster

Source: www.independent.co.uk
— 14 February 2017



Children with polio doing physiotherapy exercises at Wingfield Nuffield Orthopaedic Hospital in Oxfordshire (Rex)

A passage in Philip Roth's novel *Nemesis* describes the horror of catching polio in the US town of Newark in 1944, when outbreaks of the disease were common and each summer was spent in fear of infection.

"Finally the cataclysm began – the monstrous headache, the enfeebling exhaustion, the severe nausea, the raging fever, the unbearable muscle ache, followed in another forty-eight hours by the paralysis", it says.

Polio, or poliomyelitis, has existed for millennia. There is ancient Egyptian art which depicts a victim of the disease with a frail, deformed limb, using a staff for support.

While the paralyzing effects of polio have always been devastating, outbreaks of the disease were relatively rare in the West until the late 19th century, when major epidemics swept Europe and the US.

In Roth's story, everyone knows what polio is but no one knows where it comes from or how it spreads, with everything from flies to fast food blamed for its rapid transmission.

In fact it is passed on through contact with faecal matter, by drinking contaminated water and eating food that has been touched by the unclean hands, and sometimes through coughs and sneezes.

Once infected, the virus invades the nervous system and begins to destroy nerve cells which control the muscles, especially in the legs. If someone is paralysed by polio, there is a five to

10 per cent chance they will die when the disease reaches their respiratory system. There is no cure.

"He was there for three weeks before he no longer needed catheterisation and enemas, and they moved him upstairs and began treatment with steamed woollen hot packs wrapped around his arms and legs, all of which were initially stricken", writes Roth, of one character's experience.

"He underwent four torturous sessions of the hot packs a day, together lasting as long as four to six hours. Fortunately his respiratory muscles hadn't been affected, so he never had to be moved inside an iron lung to assist with his breathing, a prospect that he dreaded more than any other".

The iron lung was invented in 1928 by American physiologists Philip Drinker and Louis Shaw. The huge ventilator, which left only the head visible, kept polio victims alive for a number of weeks while they recovered from the illness – but those left permanently paralysed could spend their whole lives encased in one.

Dawn Varma, a 20-year-old who was paralysed by polio when she was 10 weeks' pregnant, even gave birth while she was in an iron lung.

A photograph from 1959 shows Ms Varma, the wife of an Indian scientist, inside the ventilator with a nurse tending to her healthy newborn baby, called Dilip.



Dawn Varma, who gave birth while inside an iron lung at the age of 20 (Rex)

In 1952, Jonas Salk developed an injectable polio vaccine and in 1961 Albert Sabin pioneered the oral vaccine drops, which had the advantage of spreading immunity through communities. These vaccines were highly effective, and cases in the US fell from 35,000 in 1953 to 5,300 in 1957.

(cont'd P11)

Polio Then And Now (cont'd from p10)

The new oral vaccine was approved for emergency use in Hull in 1961 when an epidemic hit the city, with parents taking their children to improvised immunisation centres in their thousands to be given sugar lumps with the vaccine.

The success of mass polio vaccination in the developed world led doctors and international humanitarian organisation Rotary International to consider its potential elsewhere.

John Sever, head of the infectious disease branch at the US National Institutes of Health and a Rotary member, in 1979 proposed the idea to the group's president [Ed. Clem Renouf], who wanted to develop a new project for Rotary that would involve the entire organisation.

"He asked my opinion of what we could do, and I wrote him: 'If a single vaccine were to be selected, I would recommend poliomyelitis'. At the time, less than half the children in the world were receiving any vaccine", Dr Sever told National Geographic.

"At the time, there had just been the last cases of polio to occur in the United States, and smallpox had just been declared to be eradicated. So people felt it was possible, that we could aim to eradicate polio".

He said soon afterwards, "the legislative body that represents all Rotarians voted that we would make immunisation for the eradication of polio our number one priority throughout the world".

That same year, Dr Sever and several fellow Rotary members travelled to the Philippines, where with the support of the government and health industry, they immunised around six million children.

Soon, the virus had been eradicated across the

Americas – a remarkable feat that led Rotary International and the World Health Organisation to announce the goal of worldwide polio eradication in 1988.

Now the disease is only endemic in three countries, Pakistan, Afghanistan and Nigeria, and there were just 37 cases last year. Optimistic health workers and organisations such as Rotary International say 2017 could be the year in which the world sees the last case of polio.

Serious challenges, including violent attacks on vaccinators by Islamists, poor routine immunisation coverage, remain.

But one day taking children to the doctor for polio vaccination drops may be a distant memory, and the long list of famous polio survivors including Francis Ford Coppola, David Starkey and Mary Berry will fade into history.

The hope generated by this possibility is summed up in Roth's novel when the protagonist listens to his grandmother reminisce about diseases of the past.

"His grandmother was remembering when whooping cough victims were required to wear armbands and how, before a vaccine was developed, the most dreaded disease in the city was diphtheria", it says.

"She remembered getting one of the first smallpox vaccinations. The site of the injection had become seriously infected, and she had a large, uneven circle of scarred flesh on her upper right arm as a result. She pushed up the half-sleeve of her housedress and extended her arm to show it to everyone".

Read more about *Nemesis* online at: www.booktopia.com.au/search.ep?keywords=philip+roth+nemesis&productType=917504

Still Here Website

This website is dedicated to Australia's tens of thousands of polio survivors and their families. The polio 'heroes' (right) were pictured at Polio Australia's first "We're Still Here!" campaign visit to Parliament House in October 2012, during national Polio Awareness Month. ●



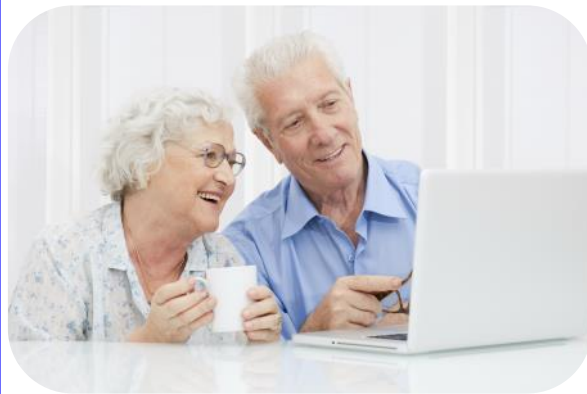
Leave your own story at: www.stillhere.org.au

Dementia Online Training

What is Dementia? and **Understanding Younger Onset Dementia** are 2 free courses available to you from Alzheimer's Australia. Each course will take you approximately 1 – 1½ hours to complete, and each course is broken up into 3 parts (topics) so you can complete these topics in short chunks if more convenient for you. Upon completion of each course, you will receive a certificate of completion.

To register for this online learning, head to:

<https://dementialearning.mygo1.com/webapp/#/access/signup> to set up your password and access the learning system.



Once you are logged in, click on the **Browse Company Courses** button (if you can't see this, you can also click on the **Dementia Learning Courses** tab up the top).

You can now locate the 2 free courses:

- **What is Dementia?**
- **Understanding Younger Onset Dementia**

Click **Review** then **ENROL** to begin.

If you have any trouble registering or accessing the courses, please do not hesitate to contact support at dementialearningsupport@alzheimers.org.au or (03) 9816 5715. ●

Just Breathe!

Welcome to the Outbreath Institute—training ground for the BreatheOutDynamic system (BODs), as described in my recently published book, *Just Breathe Out—Using Your Breath to Create a New, Healthier You*. After 9 years in the works, *Just Breathe Out* is available in bookstores and online as a soft-bound book, an e-book in kindle and nook formats, and as an iTunes audio book at audible.com. Visit www.justbreathout.com for purchase information.

To ensure that the wisdom found in *Just Breathe Out* spreads far and wide, I'm creating the OutBreath Institute to provide stepping stones for you to develop your BODs skills and to incorporate them into your daily routines.

The OutBreath Institute will include online training as well as in-person events, and welcomes the opportunity to provide training in your community. Our mission is to support your goal of reaching your highest potential. The BreatheOutDynamic system is the key. ●



Betsy Thomason, BA, RRT
www.outbreathinstitute.com

Do you or does your family member or patient have breathing muscle weakness for any reason?

If you have generalized muscle weakness, decreased breathing capacity, and a weak cough, now is the time to ASK YOUR DOCTOR about how to prevent respiratory failure and avoid invasive tubes. And if your doctor does not know about the benefits of non-invasive respiratory care, then today is the day to SHARE THIS INFORMATION with your physician.

Non-invasive ventilatory support (NVS) and mechanical insufflation-exsufflation (MIE) may help you to avoid episodes of serious breathing problems (e.g. respiratory failure), avoid the need for invasive airway tubes passed down the throat (e.g. endotracheal tubes), and avoid the need to resort to invasive airway tubes passed through the neck and into the windpipe (e.g. tracheostomy tubes), which cause increased morbidity and mortality.

www.breatheNVS.com / www.breatheBB.com

John R. Bach, MD, is a professor of Physical Medicine & Rehabilitation, professor of Neurosciences, the director of the New Jersey Medical School Muscular Dystrophy Association Clinic, and medical director of the Center for Ventilator Management Alternatives. ●

ACCC Resources For Consumers

By **Kymerly Martin**

Source: www.freedom2live.com.au — 18 January 2017

ACCC releases guidance to assist people with disability when buying goods and services. The Australian Competition and Consumer Commission and Australian Consumer Law regulators have released a range of materials that give consumers with disability useful information about their rights under Australian Consumer Law. It includes videos, fact sheets, industry guidance and a consumer guide which outline the rights and obligations of consumers and businesses in the disability sector. These have been made available to empower people with disability to use their consumer rights when buying goods and services under the NDIS.

The resources have been developed with the support of the National Disability Insurance Agency (NDIA) in consultation with disability support organisations, disability advocates and disability complaint bodies.

The ACCC has warned new and existing businesses that they must comply with their obligations under the *Competition and Consumer Act 2010*, which includes Australian Consumer Law.

"During the NDIS roll out we expect to see a range of new entrants in the market which is good for competition but we are concerned about the potential for unscrupulous traders to take advantage of vulnerable consumers", ACCC deputy chair, Delia Rickard said.

The resources are free and available from www.accc.gov.au/about-us/information-for/consumers-with-disability. Hard copies are available from local, state and territory consumer protection agencies. ●

Parliament Rejects The Omnibus Bill

Community sector welcomes Parliament's opposition to social security cuts to fund the NDIS

Source: www.acoss.org.au — 14 February 2017

Major community sector organisations representing people on low incomes welcome the Parliament's rejection of cutting \$5.5 billion from social security to fund child care and the National Disability Insurance Scheme (NDIS); and congratulates Labor, the Greens, the Nick Xenophon Team and Jacqui Lambie for continuing their opposition to these unfair cuts.

The Omnibus Bill would slash the incomes of more than two million people. We need a properly funded NDIS, but this must not be at the expense of the incomes of the poorest people in our country.

The Omnibus Bill would cut the \$38 per day Newstart Allowance by \$4 per week, despite Newstart already being well below the poverty line. A high proportion of people struggling to survive on Newstart Allowance are people with disability. If the Bill passes, Disability Support Pensioners will lose the \$7 per week Energy Supplement. People with disability should not have their incomes cut to pay for essential

supports and services they need to live their lives. The Bill would also deny young people income support for five weeks as they try to find work, and then cut their incomes by \$47 per week.

People with disability, sole parents and carers would also lose up to \$35 per week in payments assisting them with education and training. Sole parents would lose up to \$65 per week under the family payment cuts.

It is egregious to be linking these brutal social security cuts to the funding of the NDIS when the government is trying to push through \$50 billion in company tax cuts and has already passed \$4 billion in personal tax cuts for people earning \$80,000 and above.

We congratulate the Parliament on continuing its firm opposition to these grossly unfair cuts, many of which have been opposed since the 2014 budget. We call on the government to reset its agenda and look at ways to reduce inequality and poverty in Australia rather than deepen the divide by cutting the incomes of the poorest. ●

www.acoss.org.au/media_release/joint-statement-community-sector-welcomes-parliaments-opposition-to-social-security-cuts-to-fund-the-ndis/



No Jab, No Play

Pro-vaccination No Jab, No Play ads to hit our TV screens

By **Brittany Shanahan**

Source: www.heraldsun.org.au — 4 January 2017

Parents are being urged to source vaccination information from qualified medical professionals rather than “crackpots on the internet” ahead of the school year.

Under current legislation all Victorian children have to be immunised if they’re enrolled in childcare or kindergarten, unless they have a medical condition.

The anti-vaccination movement have vehemently campaigned against the State Government’s move, including sending vile and abusive messages to Health Minister Jill Hennessy.

But from January 15, an advertising campaign promoting the benefits of immunisation and the No Jab, No Play laws will hit TV screens, radio, cinemas and social media.

Dr Margaret Cooper, who features in the ad campaign and survived polio, urged parents not to listen to “nutters” against vaccination.



Dr Margaret Cooper will feature in a new ad campaign promoting the benefits of immunisation. Picture: David Smith

She said polio was a very painful inflammation of the spinal cord and brain which leads to death in up to 10 per cent of children who are paralysed.

“In my case my arm and back are seriously affected ... (and) when I was in terrible pain (as a child), I kept looking at my parents saying, why don’t you stop this?” Dr Cooper said.

“They couldn’t, but now you can vaccinate to prevent your child going through that terrible pain. Why should children suffer?”



Caitlin Mara with 15-month-old Sonny, who was born with a rare immune deficiency. Picture: David Smith

Mother, Caitlin Mara, echoed Dr Cooper’s sentiments.

Her 15-month-old boy, Sonny, was born with a rare immune deficiency that prevents him from producing his own antibodies, meaning he can’t fight off infection, and relies on others to be vaccinated.

“His body doesn’t respond to vaccinations so we believe it’s important others are immunised to help keep Sonny healthy”, she said.

Acting Premier James Merlino said the government wants to reach a 95 per cent vaccination rate which would halt the spread of dangerous and virulent disease such as measles.

“The scientific evidence is crystal clear — vaccines are safe and there is simply no excuse for not immunising your child”, Mr Merlino said.

Ms Hennessy urged parents to get information from medical professionals not “crackpots on the internet”.

“Most parents want to do the best thing but when they go online to research it’s inevitable they will come across the lies and mistruths of the anti-vaccination movement”, she said.

“We want people to talk to their GP’s about vaccinations”. ●

Promising New Approach to Making Polio Vaccines

By Marie Rosenthal, MS

Source: www.idse.net — 10 February 2017

Polio is on the verge of being eradicated worldwide, but even after eradication, vaccination will continue to prevent a reemergence of this disease. Using current technology, however, the production of vaccine requires growing enormous quantities of live virus, which is then chemically killed, bringing a security risk for virus escaping into the environment.

Scientists have identified new ways that could be used to make polio vaccine that do not require the growth of live virus for its manufacture (J Virol 2017;91:e01586-16; PLoS Pathogens 2017 [published online Jan. 19]).

Vaccine manufacturing, such as for hepatitis B and human papillomavirus, have used virus-like particles (VLPs) to create effective vaccines, but poliovirus VLPs have proved to be too unstable to be practical in vaccine production.

Now, teams are looking at ways to modify these VLPs, also known as empty capsids, to increase stability. The first group of researchers, from the University of Leeds, in the United Kingdom, identified mutations that make their structures sufficiently stable to act as vaccines. The empty capsids change shape when warmed, rendering them unstable, but the mutations identified in this research prevent these damaging changes.

These new stabilized empty capsids could become a suitable replacement for the current live attenuated poliovirus vaccines and can be produced in ways that do not require growing live virus, according to the researchers.

"Continuing to vaccinate after polio has been eradicated is essential to ensure against the disease recurring, but there are significant biosafety concerns about current production

methods", said David Rowlands, PhD, a professor of molecular virology and co-leader of the study at the university. *"Our new method of creating the vaccine has been proven to work in lab conditions, and on top of that we've proved it's actually more stable than existing vaccines".*

This in vitro study showed stabilized VLPs to be effective in a controlled environment, and animal studies are planned to ensure they will be safe and effective.

In the second study, Helen Fox and her colleagues at the National Institute for Biological Standards and Control, also in the United Kingdom, developed a new method to stabilize polio protein capsids.

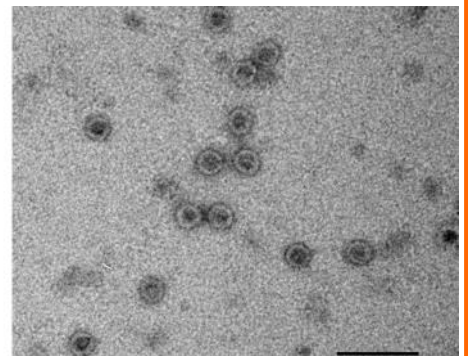
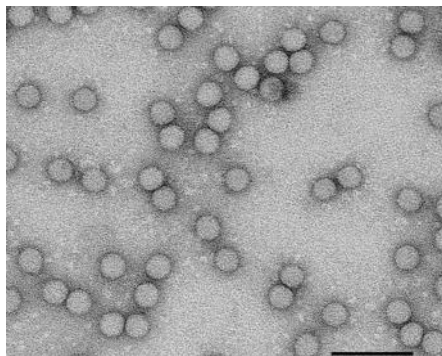
The researchers first identified mutations in the three types of poliovirus, which increased the capsid stability without altering the structures of the shells. By systematically introducing combinations of these new mutations into viruses, the scientists increased capsid stability to a level compatible with vaccine production. When tested in mice and rats, the particles caused the animals to produce high levels of protective antibodies, suggesting that they could function effectively as vaccines. Furthermore, these particles can be stored without refrigeration for many months, without significant loss of activity.

"The approach we developed was remarkably effective and worked for all three types of polio, so [it] may have applications in the design of vaccines against other virus diseases. The challenge now is to transfer these designs to production systems that can deliver large quantities cheaply so that a vaccine for global use is feasible", said Andrew Macadam, PhD, the lead scientist at NIBSC.

The improved stability of these modified capsids means they can be produced safely using bioengineering techniques.🌟

An electron micrograph of live poliovirus particles (left) and empty virus particles (right). The VLPs contain no infectious viral RNA and so the stain used to highlight them fills the empty space, making them appear black.

The bar at the bottom right of each image represents 100 nm, to give an idea of scale.



How Robots Are Helping To End Polio

Source: polioeradication.org
— 10 January 2017

Automated machines at the CDC are increasing the number of samples tested for polio and for immunity against it.

Keeping an eye on polioviruses and ensuring that children are protected around the world is a big job – and recently, we've enlisted robots to help us out.

At the US Centers for Disease Control and Prevention (CDC), the Population Immunity Team uses automated laboratory machines to test blood samples for poliovirus antibodies through a process called serological testing. These robots have significantly increased the number of samples able to be processed – from 20,000 – 30,000 tested collectively in the past two decades to 100,000 samples in 2012 alone. These machines have not only accelerated the rate of sampling, but have also led to more accurate and higher quality test results.

What the tests can tell us

Serological testing is used to assess how well a population is immunized against the three strains of polio, providing important information about the effectiveness of immunization campaigns and new vaccines undergoing preclinical and clinical trials. If antibodies are detected in a healthy person, we can conclude that they are immunised against polio. If no polio antibodies are detected, this indicates that the person either has not been immunised or that they have a compromised immune system.

Serology can also help determine if a person has polio, but it cannot serve as a diagnosis on its own. Since the tests cannot differentiate between antibodies induced by immunisation and antibodies induced by an infection, accurate medical history is important for interpreting these tests.

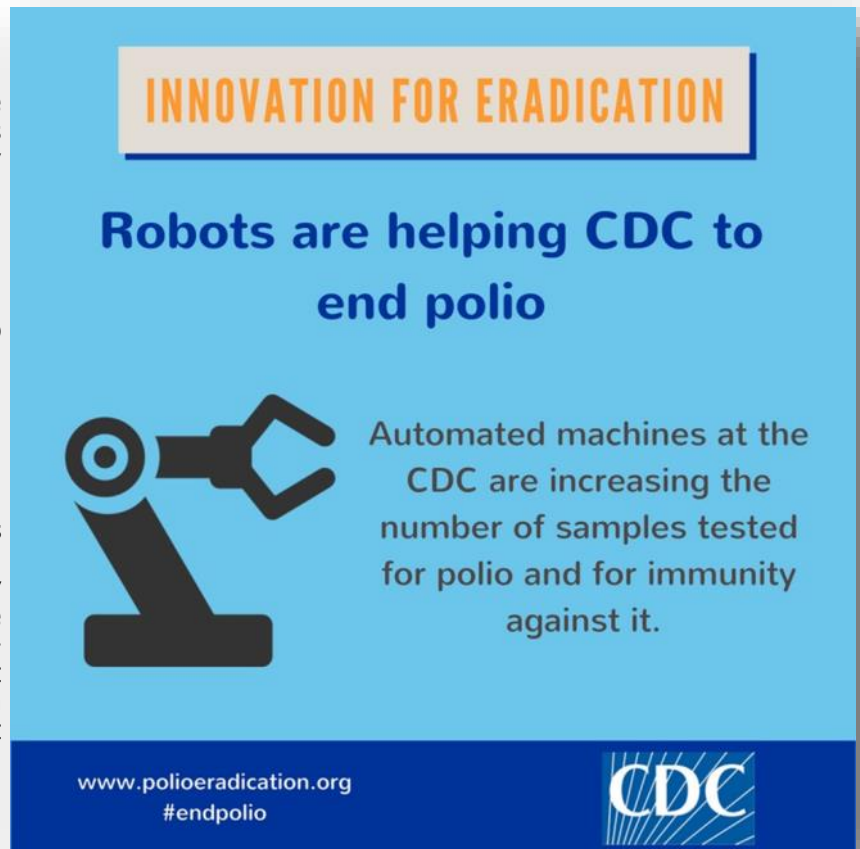
Diagnostics on the horizon

Rapid identification of possible cases is important to stopping the spread of poliovirus. In addition to the automated tests, the CDC is developing direct diagnostics, or ways to test for polio directly from stool samples. This will help to correctly identify polio cases and shave off about 10 – 14 days from the time it normally takes to get a test result.

The future of disease surveillance

High quality surveillance systems, using innovative technology like these robots, are key to ensuring that we finish the job and end polio for good.

These robots have not only helped us to get smarter about polio, but also have the potential to benefit other disease programs, including for measles, Zika and vaccine-preventable diseases. By continuing to innovate in disease surveillance, we'll be able to better control epidemics of the present and future. 🌐



<http://polioeradication.org/news-post/innovation-series-how-robots-are-helping-to-end-polio/>

Polio This Week

Source: Polio Global Eradication Initiative — as of Wednesday 15 February 2017

- The 12th meeting of the Emergency Committee under the International Health Regulations (IHR) met on 7 February and concluded that current global polio epidemiology continues to constitute a Public Health Emergency of International Concern (PHEIC). The Temporary Recommendations promulgated under the IHR remain in effect. National polio emergency action plans continue to be implemented in all countries affected by circulation of either wild poliovirus or vaccine-derived poliovirus, and all countries currently thus affected have declared these events to be a national public health emergency.
- A personal video testimonial on living with polio: Ann Lee Hussey, a polio survivor and volunteer for Rotary International, shares her story of living with polio. Her experiences drive her commitment to end the disease once and for all: www.youtube.com/watch?v=jygoO9ZelfM

Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

| Total cases | Year-to-date 2017 | | Year-to-date 2016 | | | Total in 2016 | |
|---------------------------|-------------------|-------|-------------------|-------|-----|---------------|--|
| | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV | |
| Globally | 1 | 0 | 1 | 2 | 37 | 5 | |
| —In Endemic Countries | 1 | 0 | 1 | 0 | 37 | 2 | |
| —In Non-Endemic Countries | 0 | 0 | 0 | 2 | 0 | 3 | |

Case breakdown by country

| Countries | Year-to-date 2017 | | Year-to-date 2016 | | | Total in 2016 | | Onset of paralysis of most recent case |
|----------------------------------|-------------------|-------|-------------------|-------|-----|---------------|-------------|--|
| | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV |
| Afghanistan | 1 | 0 | 0 | 0 | 13 | 0 | 13 Jan 2017 | NA |
| Lao People's Democratic Republic | 0 | 0 | 0 | 2 | 0 | 3 | NA | 11 Jan 2016 |
| Nigeria | 0 | 0 | 0 | 0 | 4 | 1 | 21 Aug 2016 | 28 Oct 2016 |
| Pakistan | 0 | 0 | 1 | 0 | 20 | 1 | 22 Dec 2016 | 17 Dec 2016 |

NA: onset of paralysis in most recent case is prior to 2015. Figures exclude non-AFP sources.



<http://polioeradication.org/polio-today/polio-now/this-week/>

Polio Australia

Representing polio survivors throughout Australia



Polio Health and Wellness Retreat

Body / Mind / Spirit

SurfAir at Marcoola, Queensland

Thursday 26, Friday 27, Saturday 28 and Sunday 29 October 2017

Expression of Interest Only

Polio Australia will once again be facilitating its 3 day Polio Health and Wellness Retreat for polio survivors and their partners/family members from Thursday 26 to Sunday 29 October, 2017 on the beautiful Sunshine Coast in Queensland. The holistic 'Body / Mind / Spirit' theme will continue and may include sessions such as:

- ◆ Interactive group sessions and one-to-one consultation opportunities with a variety of allied health professionals
- ◆ Hydrotherapy and exercise options
- ◆ Latest orthotics, aids and equipment displays
- ◆ Seated Yoga and Meditation Sessions
- ◆ Activities To Keep The Mind Active
- ◆ Creative Workshops and Singing for Health
- ◆ Massage therapy

See details of previous Retreats at www.polioaustralia.org.au/retreats

Polio Australia's Health and Wellness Retreat

26th - 29th October 2017

Approx. cost of registration fees for 3 nights accomm, all meals and most activities \$350 pp double and twin / \$450 single / small group sharing options will also be available. All fees yet to be confirmed.

Please provide me with more information on the Polio Health & Wellness Retreat when available.

Name: _____

Address: _____

Phone/s: _____ **Email:** _____

Return to: Polio Health & Wellness Retreat, Polio Australia, PO Box 500, Kew East, VIC, 3102 or Email: office@polioaustralia.org.au