

POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

At our 29th Annual General Meeting (AGM) held on 2nd December 2017 the following members were elected to the Management Committee:

Gillian Thomas
Susan Ellis
Merle Thompson
Alan Cameron
Charles Anderson
Anne Buchanan

President
Vice-President
Secretary
Treasurer

Nola Buck
Ella Gaffney
Chris Keun
Janette McKenzie
Diana O'Reilly
Shirley White

At the AGM we were sorry to farewell two stalwart members of the Committee for whom the time had come to stand down: Anne O'Halloran and John Tierney.

Anne was one of the original 1988 Working Party members tasked with setting up an information and support network for NSW and ACT polio survivors and their families. Anne was subsequently elected onto the first Management Committee in 1989 and served until 1991. She re-joined the Committee at the 1998 AGM, and served for a further three years, stepping down at the 2001 AGM. Anne again stood at the 2014 AGM and since that time has worked tirelessly as our Seminar Co-ordinator. Sadly, after nine years of dedicated service on behalf of her fellow polio survivors, Anne's health no longer allows her to continue. We are very grateful for her work over many years, and wish her well for the future.

John joined the Committee at the 2009 AGM and has served since that time – eight years, including one year as Vice President. John's primary role over this time has been as our pro bono Government lobbyist, at both the State and Federal levels. It was John's advocacy on our behalf with the NSW Health Minister that resulted in this year's review by the NSW Health Agency for *Clinical Innovation* into the needs of people living with the late effects of polio. We are hopeful that this work will lead to a model of care being developed in the NSW public health system which, for the first time, is targeted to meet the specific needs of polio survivors in this state. John is moving on to full-time retirement (having now also stepped down as President of Polio Australia), and he is looking forward to spending more time with his family – in particular his wife, Pam, and his grandchildren. We envy him now having time to smell the roses, and give our best wishes for his retirement.

Late Effects of Polio Clinical Practice Workshops

As advised in the last *Network News*, Polio Australia has received Federal Government funding over three years to conduct these workshops, and has employed Paul Cavendish, Clinical Health Educator, to deliver the program to health professionals around Australia. Since Paul commenced in September, he has held workshops in Wagga Wagga, Wollongong and Coffs Harbour. Over the first year, 16 workshops are planned around NSW/ACT. Check <www.poliohealth.org.au/workshops/> often for upcoming dates and locations, and please encourage your treating health professionals to attend when a workshop is in your area.

Walk With Me Fundraiser

Polio Australia's annual *Walk With Me* fundraiser was recently held in Brisbane and Canberra. As a participant in the Canberra Walk, the money I raise each year is shared equally between Polio Australia and Polio NSW. It is not too late to donate – simply visit <www.polioaustralia.org.au/wwm2017-canberra-gillian/>.

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How I Learned to Stop Worrying and Love Technology

By Daniel J Wilson, PhD, Professor of History, Muhlenberg College, Allentown, Pennsylvania

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I have now been struggling with the effects of post-polio syndrome for nearly thirty years. It first appeared as a weakness in my right leg, the one most affected by polio, in 1987. Over the ensuing two decades, the leg has gotten weaker and I began to have breathing problems at night. These physical problems have led to an increasing reliance on technology to help me breathe at night and to move around during the day. I have used a Bi-Pap machine at night since 2000 and since August 2006 I have used both a scooter outside my home and stair glides in the house.

Like some other polio survivors, I resisted getting the ventilator, the scooter, and the stair glides. I had not used any assistive devices since the early 1960s when I had two surgeries that necessitated using crutches for a couple of months. I was proud of my ability to get around on my own without assistance. I could never walk very far — no Appalachian Trail or marching band for me — but I got around quite easily. I associated assistive devices with disability, and I didn't consider myself disabled. Inconvenienced at times, but not disabled. Using the technology of assistive devices was something I resisted. I wanted to do it my way, even if that was increasingly painful.

My first concession to the encroaching post-polio syndrome was to begin using a Bi-Pap ventilator at night in the fall of 2000. I had spent part of that summer at San Francisco State University studying disability and disability history with 25 other scholars, some of whom had disabilities of various types. I not only studied the way in which disability is constructed by society and the ways in which those with impairments are made to feel inferior, I also observed the ways in which my colleagues used their assistive devices to function effectively and easily. When I returned to Allentown I had a sleep study done, which revealed serious sleep apnea, which explained why I was waking up tired. I wasn't happy about the doctor's recommendation of a Bi-Pap, but decided to try it. Getting used to the mask was not easy. The first couple of nights I did not get through the whole night with the mask on. By the end of the first week, when I could make it through the entire night with the machine on, I began to notice a real difference. I was sleeping through the night, instead of getting up two or three times. And in the morning, I was more wide awake and less tired. I have used it every night since, both here and in Europe, except when we have had a power outage. It goes with me when I travel and I rely on it to help me get a restful night's sleep.

In some ways, the Bi-Pap was easy, in spite of the challenges of adjusting to the mask. No one had to know except my doctor, my wife, Carol, and our dog, Abbey — who thought it was a vacuum machine when I first turned it on and fled the room. Because I used it only at night, it was a hidden technology unless I revealed the secret. Fortunately, my wife, Carol, and my dog, Abbey, both adjusted to the noise of the machine.

My next device would be more public — using a walking stick when there was snow on the walks. As my leg weakened, it became problematic to walk on uneven pavement such as those covered by snow and ice. So, about fifteen years ago I began using a walking stick in winter. It was a bright red walking stick I had purchased in the early 1990s in Zermat, Switzerland, so I could delude myself that I was getting ready to scale the Alps. At least it didn't look like I had purchased it at a medical supply store. For the last two years I have

been using the stick whenever I have any distance to walk. It helped give me stability and prevented several falls. But I could tell from the increasing pain and decreasing distance that I was willing to walk that I needed to think about getting a scooter. In the summer of 2004 I purchased a Volvo station wagon that was capable of hauling a scooter, but I wasn't yet ready to get the scooter.

Finally, this past summer of 2006 I decided it was time to get serious about a scooter and stair glides, as I was deciding not to do too many things because of the pain it would cause. I checked with friends in the support group about reliable suppliers as well as with colleagues at the Lehigh Valley Center for Independent Living, where I serve on the Board of Directors. I was able to try out three different scooters to see what worked best for me and which fit in my station wagon. My wife and I also decided to put in two stair glides. We had considered moving and had looked at ranch houses, but the prices were high and we liked the house and neighborhood we lived in. In August both stair glides were installed so that I could easily get to the upstairs and to the basement (that way I could help with laundry). I also bought a scooter (a Pride Revo) and had a lift installed in the Volvo so I could get it in and out easily. I began using these new devices immediately.

I think my biggest anxiety about these new technologies was using the scooter. Again, the stair glides were relatively hidden unless you came to the house. But the scooter would be right out there in public — no possibility of hiding if it was going to be useful. I was apprehensive about using at Muhlenberg College where I teach, but I had a few weeks before classes started to get used to using it on campus. I need not have worried. My colleagues and the students, when they arrived on campus, have been very accepting. Some have been interested in the scooter itself, others have asked about the reasons I use it, but most have simply accepted it as part of the scenery. I decided to be very open about why I need it, so I don't really mind the questions. It has made it much easier, and much less painful to get around campus. I no longer have to think "*do I really need to go to the library*" or "*do I really want to go to lunch in the union*". I just get on the scooter and go. My only challenge has been the automatic door openers. I have become the unofficial tester of door openers. The maintenance staff is very good at fixing them, but they do seem to stop working all too frequently. Winter and snow will pose another challenge, but the crews have traditionally done a good job on clearing the walks, so I am optimistic.

In addition to using the scooter at school, I have used it at Wegmans, Target, and the mall at King of Prussia. I took it to Valley Forge Park and the Allentown Art Museum. And I have been walking Abbey with the scooter. For several years our walks had been more of the "stroll and sniff" variety. She adjusted to the scooter very quickly and now enjoys longer and more vigorous walks.

As I got used to the new technologies and discovered that they were liberating in many ways, I began to think about why I, and perhaps others, so often resist using assistive technologies. After all, there are many other technologies I use without a second thought. I have worn glasses since second grade. This essay is written at the computer while listening to the radio. Technologies all. We use technology to heat and cool our homes and to transport us. But we resist when the technologies can help us deal with the impairments of post-polio. In part, that is because so much of society still views scooters or wheelchairs as emblems of disability. But if we buy into those social attitudes about assistive devices, we are the ones who become disabled. We are the ones who choose not to go places because it is too tiring or too painful. We are the ones who miss out on things we enjoy if we don't adopt the available technologies.

So far, people at the college and elsewhere are very accepting of the scooter. I have tried to project a positive approach to using it, treating it as just another piece of technology. Surely, if it is normal for many people to walk around the store talking on their cell phones (another piece of technology), it is normal for me — or you — to scooter through the same

store. I know I waited too long to get both the scooter and the stair glides, in large part because I didn't want to admit that I needed them. Polio survivors, and others who need them, will be better off if we can think of assistive technologies as just another modern technology that help us live better and easier lives. Cell phones make for better and easier communication. Scooters and stair glides make for better and easier mobility. I am not sure I really love technology, and that includes computers, cell phones, and scooters, but I know that all three have made my life easier. We don't have to embrace technology, but at least let us use the technologies that improve our lives without fear or trepidation.



Seminar Report

By Susan Ellis

Attendance to all Seminars over the last year or so has been very disappointing with numbers attending around 30, which included partners of members. A considerable amount of time and effort is required to obtain and access suitable speakers for these Seminars and to organise these events. It is embarrassing when we are not able to produce a decent 'audience' for the speakers who go to an enormous effort to prepare their presentations and travel from afar for what appears to be very little interest/support from our members. I always assure them that although numbers are low their presentation will be reported in depth in our newsletter for our 700 plus members to appreciate.

At present our Committee does not have a designated Seminar Co-ordinator and the job has fallen on the already heavily loaded shoulders of a few Committee members. If the reason for this poor attendance is, perhaps, that the content of our recent Seminars is deficient and not relevant, or that sufficient notice has not been given, then I apologise. Perhaps it is simply that as our membership ages it is becoming more difficult for individuals to attend.

I encourage those who may be able to bring new ideas, enthusiasm and skills to our Committee to come forward and enrich our efforts in order to continue providing topics of interest to our members into the future. Suggestions of possible topics, presenters and other comments from members on how to move forward would be appreciated. Perhaps it is time to be realistic and realise that Seminars are no longer feasible or worthwhile.

Last year I had difficulty keeping up with Seminar reports, and indeed the production of *Network News*, due to the time and effort it took to move and settle into our new retirement village villa after having lived for 38 years in our family home. I am now including those reports that I had 'missed' for your information and apologise for their lateness!

At the 2016 **AGM seminar**, held at Burwood RSL Club on 10th December 2016, where approximately 31 members, relatives and friends attended, the guest speaker for the afternoon was Maryann Liethof, National Program Manager for Polio Australia. Maryann gave two presentations: "*Australasia-Pacific Post-Polio Conference: Why, What and Who?*" and "*Polio Australia and Rotary District 9685 Partnership to Educate Health Professionals*".

In 2016, Maryann realised a career ambition by staging Australia's first ever "*Australasia-Pacific Post-Polio Conference – Polio: Life Stage Matters*" in Sydney. This 3-day international conference for health professionals and polio survivors attracted 230 speakers and delegates from 14 countries, and received unanimously positive reviews. Maryann's presentation focused on the outcomes from the Conference.

After attending two international Post-Polio Conferences in the USA and Amsterdam in 2014, Maryann returned to Australia and began organising a Conference to be held in Sydney. Within months the Four Seasons Hotel was selected as the venue and a contract signed with Intermedia Group/Interpoint Events as the event managers. Steering and Scientific Committees were then formed and keynote speakers invited to present.

There were 23 keynote speakers including orthotists, microbiologist, virologist, rehabilitation physicians, respiratory physicians, physiotherapists, occupational therapist, urologist, psychologist, and a medical historian. There were 38 additional oral presenters, 8 poster presentations, 85 total presentations, 8 clinical practice workshops, and a post-polio “service dreaming” workshop and panel discussion.

In summary, the post-polio service dreaming table responses were united in their wish for future polio services to flow from at least one National Centre of Excellence (CoE), but preferably one based in each State/Territory that would provide a ‘one stop shop for full assessment’.

The Conference was attended by 153 polio survivors/family/friends, 7 carers, 60 professionals (some also polio survivors), 3 students and 6 others; a total of 229 delegates from 14 countries – Australia, Canada, Denmark, India, Italy, Japan, Netherlands, New Zealand, Spain, Sri Lanka, Taiwan, Uganda, UK and USA.

Sponsorship for the Conference was given by NSW Health, GSK, ResMed, Polio Australia and Polio Health International. Trade stalls included Mt Wilga Private Hospital, Otto Bock and ResMed.

The Conference received many positive comments and was felt to be highly successful.

Maryann’s **second** presentation was about Rotary District 9685 and Polio Australia’s joint project in 2015-2016 to run Clinical Practice Workshops to educate health professionals about the late effects of polio (LEoP). Polio Australia is aware that there is currently a critical shortage of health professionals who can recognise and effectively manage the LEoP.

In 2014 Polio Australia partnered with members of its Clinical Advisory Group – a rehabilitation specialist, physiotherapist and occupational therapist – to run a pilot half day workshop in Victoria. In 2015 Polio Australia negotiated a partnership with Rotary District 9685 to run a series of Post-Polio Clinical Practice Workshops in the northern Sydney region. A member of the Clinical Advisory Group, Melissa McConaghy, a neuro-physiotherapist, was engaged to facilitate the workshops. In 2015-2016 eight workshops were successfully completed with 145 health professionals attending. Each workshop also provided a panel of 3-4 polio survivors to answer any questions.

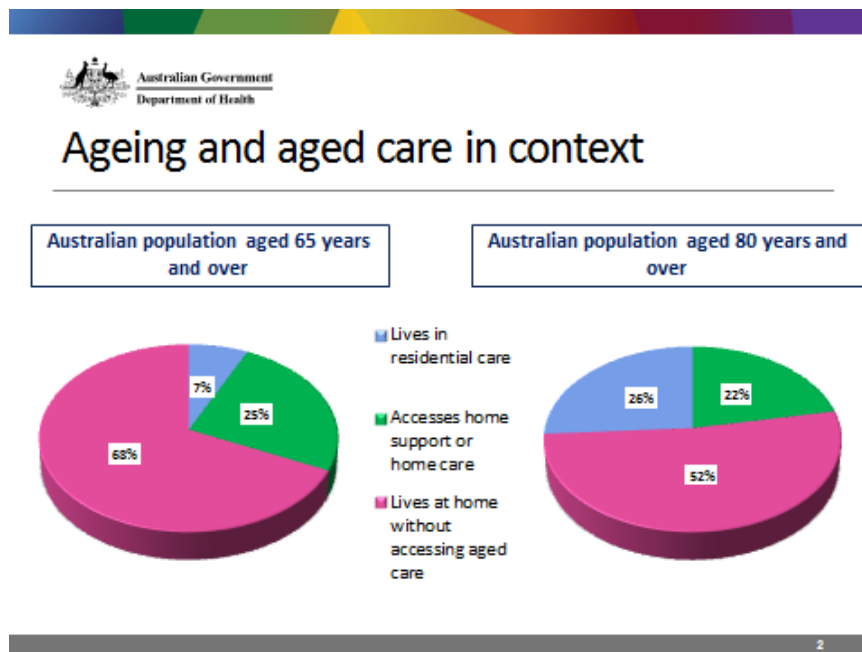
Polio Australia has since created a Health Professionals Register of skilled and knowledgeable ‘post-polio’ practitioners across many different modalities around Sydney.

Polio Australia’s long term goal is to roll out the LEoP Clinical Practice Workshops program nationally to continue expanding the knowledge base throughout the health sector, and thereby continue the work towards standardising healthcare provision for Australia’s polio survivors. To achieve this would require \$160,000 per annum. Rotary funded the initial program and Polio Australia was unable to obtain any further philanthropic or government funding for this program during the 2016-2017 financial year.

[Editor’s note: Federal government funding has since been received to continue this program over three years, commencing in late 2017.]

At the **mid-year seminar** held on Tuesday, 27th June 2017, the third speaker was Roberta Flint, Director of the federal Department of Health, speaking about “Aged Care in Australia”. This seminar was partly sponsored by Mt Wilga Private Hospital, for which we give our thanks. Roberta outlined programs that are available to members such as the Continuity of Support (or CoS) program which ensures continuing support for older people who are ineligible for the NDIS.

To find out more about CoS visit <www.health.gov.au>.



Roberta also outlined the Commonwealth Home Support program which provides services in the community and services at home, Home Care Package Services and Residential (Nursing Home) Care. A ‘one stop shop’ for information and help is offered by contacting **myagedcare** on **1800 200 422** or visit <www.myagedcare.gov.au>.

myagedcare

1800 200 422 Mon-Fri 8am - 8pm Sat 10am - 2pm

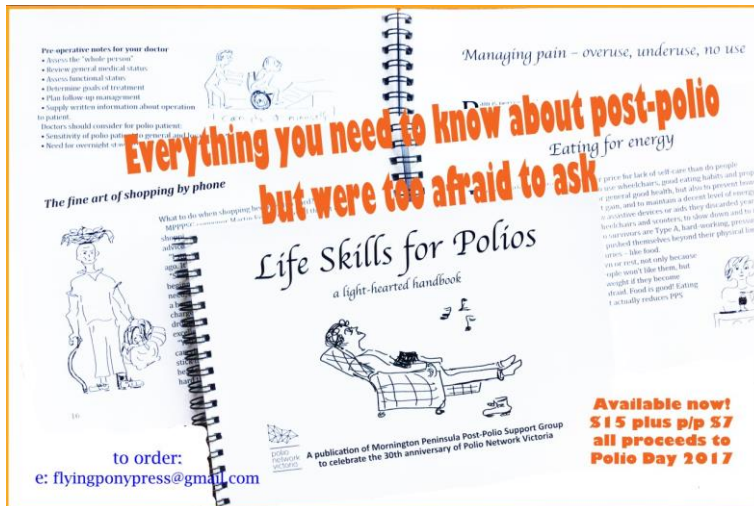
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- Other languages

Life Skills for Polios - a light hearted handbook



The exchange of ideas on management for polio survivors in the “second round” of the fight with the polio virus has proved vital. To make that trade easier, Mornington Peninsula Post-Polio Support Group has published ‘*Life Skills for Polios – a light-hearted handbook*’ to bring together the most recent, as well as tried and true, information and advice from medical experts plus those living with PPS.

The book has been compiled and illustrated by retired journalist,

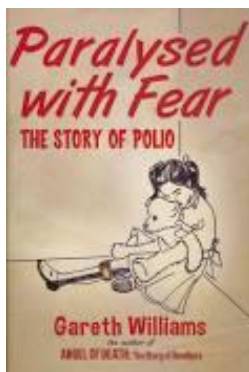
author and polio survivor Fran Henke, in themes of Home, Body and Mind – covering downsizing, tips for the kitchen and laundry, plus the big topics of pain, fatigue, exercise, and coping with past treatment in the face of the new symptoms.

Printing has been funded by generous donations from Mornington Peninsula service clubs, other support groups and individuals, with the aim of all sales proceeds going to benefit Polio Network Victoria’s Polio Day 2017.

Polio NSW has a limited number of copies of this book available for \$15 plus \$7 postage and handling. Contact our office on **02 9890 0946** to order your copy. Alternatively you can email: <flyingponypress@gmail.com> to purchase directly from Fran.

Paralysed with Fear

Reprinted from Irish Polio News, The Survivor, Autumn 2017



Paralysed with Fear is the story of Polio by Professor Gareth Williams, who was our guest speaker at the recent Conference. Gareth’s talk is on our website for anyone who missed it. If you would like to order a copy of the book, please contact the Jenner Museum Manager, Owen, by emailing: <events@edwardjenner.co.uk>.

The Edward Jenner Museum is where Jenner discovered and wrote about vaccination, and laid the ground that led to the vaccines we have today, including the ones that have all but defeated polio. Gareth says, ‘*It’s a wonderful place and a charity which is sadly running out of money and may have to close, which would be a terrible loss. Buying the book allows them to keep the bookseller’s share of the cost and so helps fundraising.*’ All Gareth’s royalties go to the British Polio Fellowship.

In the email, please confirm if you’d like the paperback or the hardback, and if you’d like the copy signed, and any special message that you’d like Gareth to include. He lives nearby and would be happy to oblige.

For more information on Dr Jenner, please see <www.jennermuseum.com>.

[Editor’s note: This book is also available from online bookstores in Australia, such as <www.fishpond.com.au>.]

What was The Iron Lung?

This interesting article was submitted by Dr Barry Baker, who has previously presented at one of our Seminars. It is reprinted from *The Oldie*, March 2017, and written by Tony Gould.

On 20th April 1959, at the age of twenty, I was admitted to the Kowloon British Military Hospital in Hong Kong with a fever. Later in the day, I found myself fighting for breath, surrounded by figures in masks and gowns, who seemed to be blocking out my air. They were intent on lifting me into a yawning box which, in my delirious state, I mistook for a coffin. Enfeebled though I was, I did all I could to resist them. But I soon gave up the struggle and sank into oblivion.

It was not a coffin, of course, but an iron lung. I had never heard of an iron lung and had no idea what was wrong with me. "A temporary form of paralysis" was all the doctor had said. But the iron lung..... This was a long cylindrical tube with portholes on either side. My body was encased in it with my head sticking out at one end. Above my head was a glass shelf, on which a book could be placed face down so that I might read if there was someone to turn the pages. There was also a sort of rear-view mirror in which I could watch the world go by.

An iron lung is a 'negative-pressure ventilator'. It works by alternately pumping air into the cylinder and sucking it out again, causing your chest to rise and fall in sync with it. It doesn't involve a surgical intervention like a tracheotomy, as positive-pressure ventilators generally do. But it is an uncomfortable – if life-saving – beast. To ensure the cylinder is airtight, your neck has to be padded with cotton wool; and to this day, if anyone puts a hand around my neck, my first impulse is to lash out. I won't wear polo-necked jumpers, or even a tie if I can avoid it.

Once you get used to the rhythmic sucking and blowing of the machine, it can be a comforting sound – like the ebb and flow of waves on the beach. But it was not always thus. Frederick B Snite, a wealthy young American who contracted polio when travelling in China in 1936, described his first iron lung as 'a threshing machine with a cold'. Yet without it he wouldn't have survived. He was lucky that one of the original sixteen respirators devised in 1928 by Philip Drinker, an engineer working at the Harvard School of Public Health, had found its way to China, courtesy of the Rockefeller Foundation, and happened to be just minutes away from where he fell ill. He was dependent on iron lungs for the rest of his life but managed to travel, get married and father three daughters, becoming something of a celebrity – second only to Franklin D Roosevelt among polio survivors in the US.

The National Foundation for Infantile Paralysis (better known as the March of Dimes), co-founded by FDR and his former legal partner Basil O'Connor in the mid-1930s, came into being at the most opportune moment for the development of iron lungs. FDR's name and O'Connor's forceful personality made this the most effective medical charity, certainly of its time and perhaps ever. Faced with a shortage of respirators and an increasing number of respiratory cases in the US polio epidemics of the 1930s, doctors had the invidious task of having to decide whose need was greatest. But logistical problems were meat and drink to O'Connor: he established respirator centres all across the States and for the next twenty years – until first the Salk and then the Sabin vaccines made them redundant – saved many lives as a result.

In this country, where respiratory polio cases also mounted during epidemics before and after the Second World War, the main benefactor was the motor manufacturer Lord Nuffield, who used his Morris Cowley works in Oxford to produce iron lungs which he distributed to hospitals in Britain and throughout the empire – including the one I occupied in Hong Kong. Respiratory technology has now moved on and polio epidemics are a thing of the past. As a result iron lungs are, for the most part, museum pieces.

By no means all polio cases required iron lungs; and iron lungs were also used for other respiratory ailments. But in people's minds the two are inextricably connected. A ward with rows and rows of iron lungs is one of the enduring images of polio – which, along with pictures of children with their legs encased in calipers, the March of Dimes did not hesitate to use for fund-raising purposes.



Joan Hume, warrior activist for disability rights

JOAN HUME 1947 – 2017 *Sydney Morning Herald*, October 3, 2017. Tribute written by Polio NSW member, Terry Fletcher.

It was 1971 and Joan Hume was a carefree 23-year-old teacher of English and History at Lurnea High School. She finished supervising students swimming and accepted a lift with a colleague back to school. The car was in a road accident throwing her onto the metal window winder, which broke her neck. She was paralysed and quadriplegic. After rehabilitation at Royal North Shore spinal unit, she returned home early as her father, a doctor, could attend her medical needs. With the support of her family and friends she picked up the threads of her former life.

Her decision to buy a home and live independently did not surprise anyone who knew Hume. She was strong-willed, determined and resilient, strengths that supported her in many future battles. She wanted to return to classroom teaching and was appointed to the correspondence school, but was shocked when the headmaster refused to provide parking or an accessible toilet and told her bluntly "*You can't come here*". When the principal of Beverley Hills High School accepted her as a member of the English History staff she was overjoyed.



Joan Hume was a lifelong campaigner for disability rights

Hume's outstanding intellect, knowledge and love of literature, archaeology and ancient history were essential resources for the cut and thrust of classroom teaching. She was afraid that students would not accept her but this changed when she intercepted a note that read, "*Isn't Ms Hume a bitch?*". Now she was accepted, she belonged with fellow women teachers who held this dubious title and was delighted.

The tough but honest inner-city kids of Cleveland Street presented a different challenge. They greeted her, "*Who the f--- are you?*". When she explained she had no feeling in her legs cheeky boys in the front row began poking her legs with pens, pencils and rulers. She'd won their respect and laughed as she told this story. She used role play, dressing kids as dummies to understand the Egyptian rite of burial and they loved it. She was the first woman in a wheelchair to teach in a classroom. When people told her she was inspirational, it drove her absolutely bonkers. She'd say, "*I am just doing what I was trained to do*".



Joan Hume at an anti-legalised euthanasia protest in Sydney, 1996. Photo: Andrew Taylor

As she went out and about Hume grew frustrated with the barriers of the built environment. She joined the board of the Australian Quadriplegic Association (now Spinal Cord Injuries Australia) and edited *Quad Wrangle*, the organisation's magazine. She bonded with fellow disabled people angry at their exclusion from community life. She argued for equal rights and became a leader of the disability rights movement in Australia.

Hume organised demonstrations including the inaccessible Eastern Suburbs Railway, which led Premier Wran to introduce the accessible taxi transport scheme. She spearheaded the protest that ended the Spastic Centre's use of beautiful young women as fundraisers for people with cerebral palsy.

When the United Nations declared 1981 *International Year of Disabled Persons* (IYDP) Hume worked voluntarily with the government secretariat on programmes to break down the barriers between people with disability and the community. In 1982 she was awarded a Medal of the Order of Australia (OAM) for her work. She was a founding member of *Women with Disabilities Australia* (WWDA) and advocated for a royal commission into the violence, sexual assaults and deaths of women in institutions as well as the community.

Hume moved to policy work in the NSW Department of Health, as advisor to the Minister for Health on disability. Her MA thesis was *The Dwarf in Recent Australian Fiction – Myths Images and Stereotypes*. In her many years in a wheelchair she found community attitudes divide into those who see you for the betterment of the community and able to make a positive contribution, and those who see you as an embarrassment and a burden on society.

In the 1990s while working in TAFE NSW as teacher consultant to students with physical disability she became ill. Chronic myeloid leukaemia was diagnosed. A life-saving drug worked for her but she lived with the knowledge it could change to the fatal acute myeloid leukaemia. Later, when bladder cancer was found, she kept up the fight.

As president of *Spinal Cord Injuries Australia* for a second term she believed the National Disability Insurance Scheme (NDIS) would not solve everything and advocacy was still needed. A founder of "Lives Worth Living", she worked against doctor-assisted death, advocating instead for support to allow people to live meaningful lives. At a recent dinner party a woman said to Hume, "*If I had what happened to you I would have committed suicide*". Such comments she found difficult to live with, but Hume lived a positive life even during the darkest times.

In 2015 the University of Sydney awarded her the prestigious *Alumni in Community Achievement* for her lifelong advocacy for the rights of people with disability. She was also one of nine leaders in Disability Rights in Australia portrayed in the Australian Museum of Democracy.

There was always a book in her handbag and the newspaper. One never knew when a lull in a meeting might give her a chance to complete the crossword. She was known for her satirical under-breath quips whenever some outrageous comment was made about disability. The disability community loved her dearly. The day of her funeral it rained constantly. In a way the rain reflected the grief and tears of many of the 500 mourners who gathered to honour and farewell a magnificent warrior who'd dedicated her life fighting for the rights of people with disability.



The following articles are reprinted from Newsletter of IDEAS November/December 2017



e-Bility is our one stop online classifieds shop for all things accessible. You can advertise your disability equipment and furniture, modified vehicles or accessible properties on our classifieds website and get your excess clutter out of your life and into the hands of people who really need it! (At the same time you can see what you might like to purchase.)

IDEAS purchased e-Bility in 2015 and since then we have been helping people to buy and sell their second hand disability equipment, accessible vehicles and properties!

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www.e-bility.com

1800 029 904

email: sales@e-bility.com

CLASSIFIED PRICES: Rates – per 60 days

Type	Private Rate	Commercial Rate
Vehicles (Used & New)	\$ 55.00	\$ 88.00
Equipment (General & Paediatric)	\$ 22.00	\$ 33.00
Vehicle Parts & Accessories	\$ 38.50	\$ 49.50
Accessible Properties for Sale	\$396.00	\$396.00

All prices include GST

Happy Travelling - Australian Beach Accessibility

All Australians, including the 4 million people with a disability, deserve to be able to access the beach. This vision is becoming more of a reality, thanks to the support of many organisations and individuals who fundraise for the provision of equipment in order to make this possible.

In NSW, the following beaches are accessible or have equipment to hire:

Ballina – Lighthouse Beach and Avoca Beach have accessible beach matting (a portable and removable access pathway for wheelchair users, prams and bike users).

Beach wheelchairs are available to hire at:

Bermagui Surf Life Saving Club – 0459 238 442, <www.bermaguists.org.au>.

Bilgola Surf Life Saving Club – soft balloon tyre wheelchair – bookings required, phone 02 9918 2337 or email <bilgola@surflifesaving.com.au>.

Collaroy Beach Reserve – beach lifeguards, 02 9982 9261, both freewheeler and submersible chairs available, there is also an accessible change table with adult change table and hoist using the MLAK key.

Coffs Harbour – Coffs Harbour City Council 02 6648 4000, ask for the Life Guard (1 chair, free), Coffs Harbour Yacht Club, 02 6652 4390, (1 chair no pre-bookings), Northcott Society, 02 6651 2366, (1 chair, hire fee and a deposit applies for non Northcott clients), Chairs available at Park Beach Surf Club 02 6652 9870, Sawtell Surf Lifesaving Club 02 6653 2164.

Manly – free loan of beach wheelchair available from the lifeguard at South Steyne Surf Pavilion, 02 9976 1497.

Bondi – accessible promenade, beach access by ramps, accessible toilet facilities at Bondi Pavilion using MLAK key, beach wheelchair available from lifeguard.

Northern Beaches – freewheeler chair available, ramp access and can be booked through Newport Surf Life Saving Club, 02 9997 6274 on weekends, and 0418 628 362 weekdays or email <admin@newportsurfclub.com.au>.

Newcastle & Central Coast – Cooks Hills Surf Life Saving Club has a Lasher sports beach wheelchair and a sling and hoist.

Communication and Technology - Be My Eyes App

Be My Eyes is an online app that allows blind and vision impaired people to request help from a sighted person. It helps to distinguish between household products, reading instructions, or to help with a technical difficulty. The *Be My Eyes* app is only a click away to help. There are over half a million volunteers worldwide on the *Be My Eyes* volunteer database.

The person requesting help clicks a button which starts a live video connection between the blind or visually impaired user and the sighted person.

When the person requesting help logs into the app, there is a button that reads “connect to first available volunteer” which the person taps. *Be My Eyes* calls a sighted volunteer (who speaks in their language) and establishes a video between the person needing help, through their phone’s camera, and both participants’ microphones. The sighted volunteer will explain what the thing is that the camera is pointed at.

The *Be My Eyes* app can be downloaded from the Apple App Store, and is available for Android on Google Play.

Information sourced from Be My Eyes and Media Access Australia.

NDIS - HOT TIPS

Reprinted from the newsletter The DAISI link – Spring 2017



What are the steps to getting support through the NDIS?

1. Check eligibility using the online NDIS Access Checklist at www.ndis.gov.au
2. Contact the NDIA on **1800 800 110**
3. Complete an Access Request Form
4. Prepare for the planning meeting, think about needs and goals
5. Develop the plan and consider how to manage the supports
6. Carers: complete the ‘Mental Health Carer Checklist’
<https://goo.gl/AGCtRb> (type this into your browser)
7. Meet with the NDIA planner
8. Fill out a Planning Workbook
9. Implement the plan, find service providers and access supports
10. Review the plan

What doesn’t the NDIS fund?

There are rules for the NDIS that mean some supports cannot be funded in an NDIS plan. The NDIS will not fund:

- Supports that are not related to a person’s disability such as health conditions like asthma.
- Supports that are funded by a different system, such as medical costs through Medicare.
- Day-to-day living costs that everyone pays for such as food, electricity and water.

How does mental health fit in with the NDIS?

The NDIS is not just for people with physical disability, it will also provide support for people with psychosocial disability associated with mental health issues.

To be eligible for support, individuals must:

Have an impairment or condition which is likely to be permanent (i.e. it is likely to be life-long) and which substantially reduces their ability to undertake certain activities or to perform tasks unless they have:

- assistance from other people, assistive technology or equipment; or
- they can't participate effectively even with assistance; and
- their impairment affects their social and economic participation; and
- they are likely to require support under the NDIS for their lifetime.

An impairment which varies in intensity, for example because it is episodic (on and off), may still be considered 'permanent' by the NDIA despite variations in support needs.

Policy & Advocacy - Squeaky Wheel

The following articles are reprinted with permission from Spinal Cord Injury Australia's *Accord Magazine*, Spring 2017, <www.scia.org.au>. Polio NSW acknowledges SCIA's 50 year anniversary and would like to congratulate them on the many achievements and successes that this represents.

NDIS – the cost of control and choice?

The National Disability Insurance Scheme (NDIS) should give people with disability greater choice and control over much-needed support services to enable them to participate in the social and economic life of Australia.

However, the NDIS has resulted in a number of unexpected negative impacts on people with disability as well as on a number of disability support services which will lose their recurrent annual state and territory government funding from 1 July 2018. This means that many organisations, including our own advice and information service, peer support, occasional and emergency care service as well as a portion of its systemic advocacy service will need to find alternative funding. To try and address this we have accepted an invitation to join a lobby group of disability organisations to campaign for current funding to continue.

The loss of such long-standing services will adversely affect many people with disability who may be unable to seek timely specialist information and referral. As the NDIS aims to increase people with disabilities' social participation, it seems contradictory to discontinue funding for the information and referral services required when planning a holiday, researching assistive technology for home, study or work, sport and recreation, undertaking home modifications and maintenance, vehicle conversions and modifications, seeking personal care services and respite services, to name just a few. There is also the potential loss of the accumulated wealth of online and physical resources as well as the knowledge and expertise of staff, including key personnel with the lived experience of disability.

The National Disability Insurance Agency (NDIA) has recognised that information and advocacy services are outside its funding responsibility and there is no NDIS participant funding component for information and advocacy. The Federal Government historically funded a number of individual, systemic and legal advocacy services under the National Disability Advocacy Program (NDAP), but these services will now need to be funded by alternative funding sources when federal funding ceases in 2018.

Separate to the individual advocacy and information needs of people with disability, a number of the state and territory funded advocacy services don't provide individual advocacy; they are funded only for systemic advocacy aimed at addressing issues that affect large groups or all people with disability. The good news is that the Federal Department of Social Services (DSS) announced in August 2017 that it will continue funding the NDAP, as well as the NDIS Appeals Program, until 30 June 2020.

However, if there isn't any increase in the NDAP annual budget to cover the additional cost of doing so, it will most likely create a backlog and unacceptable waitlist for those seeking much-needed individual advocacy.

Spinal Cord Injuries Australia (SCIA) may be calling on members and the spinal cord injury community to assist with the campaign to seek additional ongoing advocacy and funding. This may include asking individuals to contact local politicians, emailing the relevant ministers and shadow ministers and possibly attending a rally or protest. Please contact the policy and advocacy team if you're willing to participate.

Mobility Allowance debate heats up

As mentioned in previous issues of *Accord*, the Federal Government is reviewing the Mobility Allowance to align eligibility with the NDIS. The Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016 is due to be debated in the Senate and, if passed, will mean people with disability over the age of 65 years who volunteer will no longer be eligible for Mobility Allowance for their travel costs to and from their volunteer role.

We've discovered an anomaly in this regard which is going to negatively financially impact some people with disability. The main issue is that those who are on a Disability Support Pension (DSP) or other Centrelink payment, and not the Mobility Allowance, who transition to the NDIS and successfully seek and maintain full-time employment, may qualify for an NDIS Transport Package, but will no longer be eligible for the Healthcare Card (HCC) linked to the Mobility Allowance. This is important because the HCC provides access to Pharmaceutical Benefits Scheme (PBS) items at concessional rates.

It seems contradictory – and indeed at odds with the aims of the NDIS – that the Federal Government is removing access to the HCC in this way. For many people with disability this will be a major disincentive to seek and maintain fulltime employment.

The policy and advocacy team have written to Christian Porter MP, Minister for Social Services, to raise these concerns and will report the outcome in the next issue of *Accord*.

Scooters speed into spotlight

In early September, National Party Senator John "Wacka" Williams revealed that his partner, Nancy Chapel, had stepped out from her office in regional New South Wales and was hit by a mobility scooter. A witness reported seeing Ms Chapel become airborne and land on her side, resulting in her hospitalisation and undergoing a total hip replacement.

Leader of the Nationals and Deputy Prime Minister, Barnaby Joyce, has previously backed Senator Williams' calls for more stringent regulation in relation to mobility devices. Because of this recent unfortunate incident, Senator Williams now wants his party to endorse a proposal which he regards as a public safety measure: limiting the speed of these mobility scooters from the maximum 10kms per hour to walking pace of 6kms per hour. In a motion prepared for a recent Nationals' Federal Conference, the Senator also called for the outlawing of any mobility scooters weighing – when unoccupied – more than 150kgs.

SCIA acknowledges that mobility scooter and power wheelchair users need to take responsibility and exercise due care, particularly in relation to their proximity to pedestrians. SCIA also acknowledges that pedestrians need to act similarly when using pavements, especially when stepping out of buildings that could potentially place them in the path of a moving scooter or wheelchair. Notwithstanding the seriousness of the injuries sustained by the Senator's partner, this seems to be an isolated incident which has been met by a knee-jerk reaction.

If this proposal was to be implemented, it would have an immediate and ongoing negative impact on people with severe disability. It would also greatly affect our ageing population, who are the group most reliant on these types of mobility devices. A change in the law would be particularly challenging for those living in suburbs experiencing heavy footpath traffic, and for those living in rural and regional areas who rely on mobility devices to travel long distances – in many instances leading to far longer travelling times.

Whilst SCIA understands the Senator's concern, it is not in favour of his proposal. SCIA believes the solution is scooter-user education to ensure users operate their vehicle safely and employ appropriate driver etiquette when amongst pedestrians, including reducing speed and always travelling on the kerb side of the footpath. There is also a need for pedestrians to take greater care when sharing a pathway with scooter and wheelchair traffic – the same care they'd take with cars when crossing a road, for example.

In the interim, we encourage everyone to contact their local and federal members, together with the Nationals at <www.nationals.org.au/contact/>, to voice their concerns and request that the Nationals reconsider this proposal.

Marmaduke Loke Coming to New Zealand and Australia 2018

An Opportunity for a Better Life!

Marmaduke Loke, an American Prosthetist and Orthotist, was a Keynote Presenter at Polio Australia's Conference, *Polio – Life Stage Matters*, which was held in Sydney in September 2016. He spoke of a revolutionary dynamic brace (caliper, orthosis) and showed post-polios walking in the brace. They said the brace gave them a better life.

Marmaduke is coming to New Zealand in the 3rd week of February 2018 and he will come to Australia either before or after New Zealand provided there are more than 3 people wishing to see him.

First, Marmaduke needs a video of you to see if he can do something and, if he can, an assessment would be done in Australia, followed later by fitting and training. A strong commitment to learn to walk in a different way is essential and can take up to a year. To view the dynamic brace the website is: <www.DynamicBracingSolutions.net>.

If you are interested, instructions for the video, cost, further information, and New Zealand contact details will be sent to you.

Contact: Terry Fletcher – Email: <disaware@bigpond.com>
Mobile: 0412 903 639 Phone: 02 9398 7820

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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 2,850 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.australianpolioregister.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.

Merry Christmas and a Happy New Year



The Management Committee wishes each and every member and your families a joyous Christmas and a healthy New Year



Polio Oz News

December 2017 – Summer Edition

2017 Polio Health and Wellness Retreat Review



All Retreat photos and available handouts can be viewed and downloaded from [here](#)

The following letter was received from one of the Retreat participants, Julie Volkmar. We thought, who better to give a summary of the event? The 2018 Retreat will be held in October in Adelaide. More details to come in 2018 editions of *Polio Oz News*.

Dear Polio Australia,

Thank you for the wonderful experience of the Polio Australia Health and Wellness Retreat over this past weekend. When I saw an email with one vacancy left for a female share room, my subconscious decided for me. As it turned out, my roommate was Sandra from near Cairns who I'd met but not known before. It was a mutually delightful pairing and sharing.

Hallowe'en weekend was my 65th anniversary of polio, my reason for coming. I was 14 then and lived in a town near the capital of Ohio, Columbus. After two days of increasing illness then unsuccessful raps on my knees by my doctor, I was whisked off by ambulance to the Children's Hospital in Columbus. My brother, then seven years old, told me recently how disappointed he was that the ambulance/hearse did not have its sirens going! But I'll never forget its flashing red lights as it raced the miles to the hospital – they replay in my mind as I write.

In hospital I lay in foetal position for the spinal tap that confirmed my doctor's assessment – POLIO. It must have been a Tuesday as the hospital intercom began preliminary reports of Dwight D Eisenhower's presidential election results. And so it began.

I had two concerns about attending the retreat: 1) whether I could actually get on and off the airport shuttle up the coast from Brisbane airport to Marcoola without damaging injured muscles, and 2) whether I would collapse in overwhelming compassion, recognition and grief when meeting 59 other 'polio people'. For the first, there were actually *two separate vehicles each way* between the airport and the resort but no lasting damage. And the second concern simply did not happen. Compassion, yes. Recognition, absolutely. Grief, never. Everyone was so inspiring, so interesting, so welcoming. My overriding memory is how much others struggled as tiny children, hearing what many went through, seeing how beautiful they are, and acknowledging how very fortunate I am.

Paul Constable-Calcott was extraordinary and a marvellous beginning!

Dr Neala Milburn was excellent, comprehensive and understandable, and I'd love to have a copy of her talk.

(cont'd P5)

Polio Australia

Representing polio survivors
throughout Australia

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Outgoing President's Report

*Dr John Tierney OAM
Outgoing President*

I have just returned from the Polio Australia AGM and *Walk With Me* fundraising event in Canberra. This year, between Brisbane and Canberra, we raised a record **\$25,578** dollars to date.

My special thanks go to the Polio Australia Board members who took part and the strong showing from the Canberra post-polio support group. Most of the money was raised by Sue Mackenzie, our independent Board member who organised the Brisbane *Walk With Me* event. Our special thanks go to Rotary for their support of the Brisbane *Walk*.

The Canberra *Walk* was preceded by a morning tea in Parliament House where we took the opportunity to thank the Federal government for their \$450,000 dollar contribution over three years to our *LEoP Clinical Practice Workshops* for Health Professionals. The government was represented by Mark Coulton MP, Deputy Speaker of the House of Representatives and Co-Chair of the Parliamentary Friends of Polio Survivors. Mark has been a great supporter on our long journey to finally making the breakthrough with government funding this year.

At the event, Paul Cavendish, Polio Australia's new Clinical Health Educator, made a ten minute PowerPoint presentation on the initial success of this year's Clinical Practice Workshops. The future program was outlined, including the Australia-wide location of the planned workshops being set up for 2018. Hopefully, by this time next year, there may be a health professional in your area who has an understanding of the LEOp condition and how to help you

manage it.

The Federal government funding has been augmented by a \$200,000 grant over two years from *Spinal Life Australia*, for the development of self-sustaining funding strategies to 'future proof' Polio Australia. This has enabled our organisation to fund new staff and programs and provide our National Program Manager, Maryann Liethof, with the resources she needs to turbo charge our programs.

In late October, we headed north to Queensland's Sunshine Coast for Polio Australia's seventh annual Retreat. As usual, Maryann did a brilliant job, made easier for her this year thanks to the assistance of new staff. From the wide range of presenters on the themes of Body, Mind and Spirit, we all gained new insights into how to manage our LEOp condition.

The very strong link that has been forged between Polio Australia and Polio New Zealand continues. In October, I headed across the ditch again to take part in their second Health and Wellness Retreat in Rotorua at the QE2 rehabilitation facility, which has two thermal pools (hot and very hot). In recent times, a number of executive members of Polio NZ have also attended our Retreats in Australia and in 2016 sent the largest international contingent to our Asia-Pacific Post-Polio Conference in Sydney. Both national polio organisations have learnt a lot from each other, so long may the partnership continue.

When I became Polio Australia's President in 2012, my main objective was to achieve both a proper funding base for Polio Australia and to employ with this money, sufficient staff to run our world-class programs in support of Australia's 400,000 polio survivors.

(cont'd P3)

From the Editor



Maryann Liethof
Editor

I just can't tell you how incredibly pleased I am with all the 'wins' Polio Australia has had in the second half of this year! After nearly 10 years, the relief of finally having 'real' resources at our disposal is the best gift I could ever have wished for. It's the perfect way to finish off 2017, and I look forward to a whole new game plan in 2018.

Since August, I have very much enjoyed working with Rachel and Paul (p5), and am now thrilled that Bonnie will be working on improving our financial security in the new year (p7).

Of course, much of this was made possible thanks to outgoing President, John Tierney's, exceptional government lobbying efforts, a skill set we are unlikely to see the likes of again. John, you will be missed!

With John's retirement, we welcome back our inaugural President, Gillian Thomas (p4), who is also the President of Polio NSW. Gillian seems to



revel in throwing herself into every 'deep end' she can find! Or, more likely, all our Board are 10 years older than when we first came together, and Gillian happens to be one of the 'younger' ones! As our Business Manager and web-guru, Gillian has always been beaver away in the background, and we really couldn't function without her.

The following pages contain articles on Polio Australia's Health and Wellness Retreat, the Launch of the LEOP Clinical Practice Workshops, the two *Walk With Me* fundraising activities held in Brisbane and Canberra, and a summary of the new polio movie "*Breathe*".

You can also read how Polio Australia partnered with Global Citizen to speak at this year's World Polio Day commemorations at Parliament House in Canberra in support of funding the Global Polio Eradication initiative (p10). As always, there is a varied collection of studies and articles from Australia and abroad, which will be relevant for many.

'Pace yourself' with this edition of *Polio Oz News*—it's now time for family, friends and fun! Very best wishes for the Season! 🌟

Maryann

Outgoing President's Report (cont'd from P2)

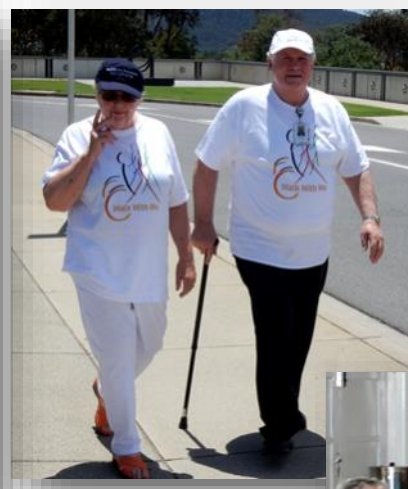
This was achieved last July, so it is now time for me to move on to full-time retirement.

Finally, I would like to especially thank Maryann Liethof and Gillian Thomas who continue to give their all to our vital work in support of Australia's post-polio community. The three of us formed the 'engine room' over the last five years and, without any support staff, made everything happen for Polio Australia. I will miss them and their brilliant work very much in the future (except for Maryann's daily email avalanche). I wish Polio Australia all the best for the future, although as National Patron, I am sure that I will be called on from time to time to assist with government affairs. 🌟

John



John holding up his 'Retirement Trophy' presented in Canberra



Left: Pam and John Tierney at Walk With Me Canberra event

Below: John (left) at Polio NZ Retreat, speaking with President, Barry Holland (standing)



From The Incoming President



Gillian Thomas

As John noted in his President's Report, he has decided that the time has come to retire (again). Over the five years that he was at the helm of Polio Australia, John's leadership, pro bono lobbying, and financial support through his Walk With Me fundraising efforts and donations have been vital in helping to assure the long-term viability of Polio Australia. We are also grateful that John will

continue as our National Patron, so his wisdom and advice won't be lost to us.

While at Parliament House for our Walk With Me event, I presented John with a memento of his time with us, in a public acknowledgement of his efforts on behalf of Australia's many polio survivors. The jade glass award is, naturally, in the shape of the polio virus! The award reads:

***In great appreciation for your
many years of dedicated service
and leadership at Polio Australia.***

***A time to look back with admiration...
A time to look forward with anticipation***

At Polio Australia's ninth Annual General Meeting,

also held in Canberra, I was honoured to be elected as President. As detailed in our [2016-2017 Annual Report](#), John's work leaves us in a strong position to move forward, and I am excited by the challenge that awaits us as our team and our programs expand thanks to the funding now made available. It was therefore timely that a new three-year strategic plan was due and, following the AGM, the Polio Australia Board and staff participated in a lively session to map a path through to the end of 2020. You can view and download our previous strategic plans [here](#), and the 2018-2020 plan will be uploaded once it has been finalised and signed off by the Board.

Finally, with John's departure, we welcomed Alan Cameron as Polio NSW's second Board member. Alan has been the Polio NSW Treasurer since 2008 and his business acumen will be an asset to the Board.

All that is left to do is to wish our readers a joyous Christmas and a peaceful and healthy New Year. 🌟

Gillian



Parliament House—Launch of Clinical Workshops

On Thursday 30 November, Polio Australia's Board was joined by the ACT Polio Support Group's members, and a number of other polio survivors and supporters, at a Morning Tea and Launch of Polio Australia's LEOP Clinical Practice Workshops Program. Our long-time supporter and Parliamentary Patron, Mark Coulton MP, provided the background to the Federal Department of Health funding, which made this program possible.

Although we originally had The Hon Greg Hunt MP, Minister for Health, lined up to do the Launch, this just happened to be the week when the Prime Minister decided to suspend the House of Representatives for a week. Minister Hunt's office suggested The Hon Ken Wyatt OAM MP, Minister for Aged Care, but he was also unable to attend. We were delighted that Mark could step in, especially as he has been along on our lobbying journey since 2010.



The 40 people present were treated to a lovely lunch before heading off on the *Walk With Me* activity. 🌟

— Ed

2017 Polio Health and Wellness Retreat Review *(cont'd from P1)*

The Mobility session was useful for my own question about walkers but especially for the insight it gave me into the concerns and battles of others more severely affected. My Physio consultation was useful although we had to touch very generally in the session, and Healthy Eating reminded me of what I know and aim to practice but also emphasised the need to check product ingredients to avoid nasties, which I will. Negotiating My Aged Care by Rhee Duthie was brilliant. She's an exceptional presenter with a wonderful manner and highly knowledgeable. This session speeds my quest to see where I stand – or rather, wheely-walk! The film Immortal Life of Henrietta Lacks was astonishing, important, disturbing and very powerful. I will now read the book, thank you! And we're only half through the weekend!

Investigating the Healthy Mind by Corey Jackson and his follow up session were high on my list to attend and they did not disappoint. I'm working with a counsellor on these issues right now and have some basic understanding but I feel more

confident now and will persevere. I missed part of Write Your Story but the excellent handout is a fine resource. I do a lot of writing – journals, reflection, letters and local history – and found the notes more generally applicable. Live Love Life Colourfully was a hoot! Helpful and just plain fun, lots of laughter!

Spirit, the opening session on Sunday, was intriguing, a lively bundle of personal experiences of all things spiritual! Introduction to Buddhism fed my long-term interest and will be followed by meditation practice at the Buddhist Centre in Cairns and/or on my own.

And so I thank you for that marvellous opportunity to learn among such wonderful people, to share questions and experiences, to evaluate my own responses, feelings, needs and strengths. I come away with the knowledge that while polio has most certainly shaped me, it does not define me.

Gratefully,
Julia Volkmar 🌈

LEoP Clinical Practice Workshops



L-R: Maryann Liethof, Rachel Ingram and Paul Cavendish

By Paul Cavendish

– Clinical Health Educator, Polio Australia

The role of a Clinical Health Educator is new to everyone in the polio community, and an exciting opportunity both for Polio Australia and myself, as we try to improve the knowledge and treatment of polio's late effects in the community.

I commenced in the role on 11/09/2017 and spent two very intensive weeks with our Program Manager, Maryann and Health Promotions Officer, Rachel. It was great to be in Melbourne and meet a number of health and medical professionals with knowledge of the Late Effects of Polio (LEoP), all of whom were very generous with their time. I have also been getting out and about to meet more polio survivors, an ongoing activity which I am keen to continue.

Polio Australia received Federal funding from the Department of Health this financial year to run Clinical Practice Workshops on the Late Effects of Polio. We are currently negotiating and locking in venues in each state/territory and encourage everyone to promote these to any treating health and medical professionals you may know. We have a list of all scheduled Workshops on our website: www.poliohealth.org.au. The Workshops are aimed at allied and other health professionals, and cover material on the polio virus, a brief history of polio in Australia, recovery and rehabilitation from acute onset of the polio virus, and the effects of polio; neurological, musculoskeletal and respiratory function. We discuss the treatment options and evidence surrounding these effects, including the role of exercise; when it is appropriate and when it's not, for muscles that have been affected by polio. This is a topic which has caused many counter-productive and adverse effects in the past.

(cont'd P6)

LEoP Clinical Practice Workshops *(cont'd from P5)*

As we deliver the Workshops, it is my aim to build networks within each location. Polio Australia already has a register for Health Professionals who have skills and knowledge regarding polio: www.poliohealth.org.au/post-polio-health-professionals. This helps with referrals between professionals and also for polio survivors to find health professionals who have experience, and an interest, in working with them. We are also trying to link members of the community together. This may be through linking universities with our Workshops, amongst the Workshop participants, or assisting outpatient or community clinical teams with the skills and clinical knowledge to treat and manage a person with the LEOp in the future.

I am also interested in connecting more with polio support groups and hearing what information would assist them, or information to pass on to family or treating professionals. Please feel free to send me an email or call to discuss the possibility of meeting up in your area: paul@polioaustralia.org.au or 0466 719 013.

Some highlights so far have been the two Retreats in New Zealand and Queensland during October, and the November launch of the

Workshops in conjunction with the "Walk With Me" activity and AGM in Canberra. The Retreats allow people to come together and learn from shared experience, meet other professionals who can provide advice and assistance, and simply have some fun. This time spent with polio survivors, who all shared their stories, allowed me to see that while every person is different, (polio certainly didn't discriminate), there is still a bond and 'can-do' attitude that is shared amongst everyone I met.

"... time spent with polio survivors ... allowed me to see that while every person is different ... there is still a bond and 'can-do' attitude that is shared amongst everyone I met".

Being in Canberra provided me with an opportunity to deliver Workshops in both Wagga Wagga and Canberra, either side of the AGM. It was great to meet members of the Board from around Australia. It is inspiring to meet people who are passionate and have been working so hard to make a difference for so long. Everyone is positive, and at this moment in time, there is much to be positive about, with our Workshops and the support of others within Polio Australia to increase visibility and secure ongoing funding. I will have run 5 Workshops by the end of this year, and have 56 Workshops planned over the next 12-month period. I look forward to providing you further updates and meeting many more of you soon. 🌟

Life Skills For Polios—a light-hearted handbook

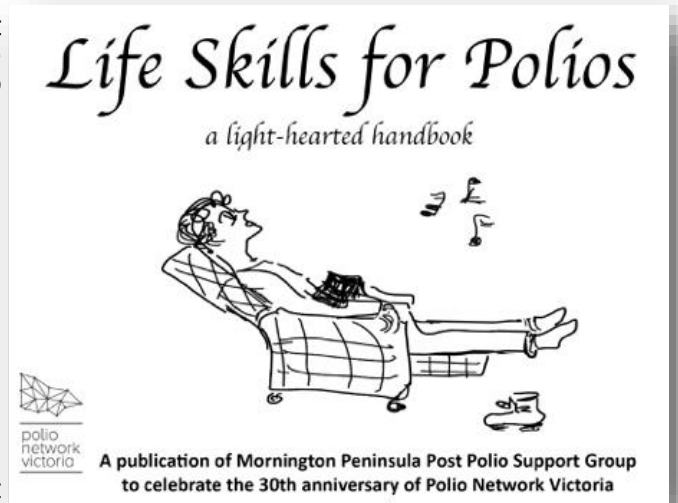
Everything you wanted to know about post-polio but were too afraid to ask? Oh really! Yes, this is the ideal book for those maybe in denial, wanting to know how to manage not only post-polio symptoms, but how gracefully to:

- go shopping when supermarkets are too big, too far;
- downsize home and life;
- demand the right chair;
- avoid falls and worse problems;
- manage the big four painful body parts;
- exercise without overdoing it;
- and find much needed sleep.

Life Skills also tackles seriously hard to talk about and unexpected polio-related outcomes like incontinence; dealing with anaesthetists; recognizing heat and cold intolerance; embracing the brace; and coping with childhood abuse.

Retired Australian journalist, artist, author and polio survivor Fran Henke, has gathered the latest information from world polio experts and lived experts, to bring together a wide range of solutions to the diverse issues that affect polios. 'Life Skills' with Fran's quirky illustrations may also help families and carers appreciate what's going on.

Cost is \$15 plus \$7 postage. Email: flyingponypress@gmail.com to order. 🌟



Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 July to 30 September 2017. Without which, we could not pay our rent, outgoing expenses, or management staff!

Hall of Fame

Name	Donation
Laurence Peter Gordon Bequest	\$25,000
Margery Kennett	\$1,000
Jill Pickering	\$1,000
Total—\$27,000	

General Donations

Trevor Bartrouney	Jill Burn	Gordon Jackman	David Miller
Terry Murphy	Meg Perkins	Liz Telford	Gillian Thomas
Total—\$1,690			

<i>Walk With Me Donations (as at 8 December)</i>	Donation
<i>Walk With Me—Sue Mackenzie—Brisbane</i>	\$15,468.04
<i>Walk With Me—John Tierney—Canberra</i>	\$6,700.00
<i>Walk With Me—Gillian Thomas—Canberra</i>	\$2,885.00
<i>Walk With Me—Brett Howard and Peter Wiergenga—Canberra</i>	\$475.00
<i>Walk With Me—Tessa Jupp and Jenny Jones—Canberra</i>	\$50.00
Total—\$25,578.04	

Grand Total—\$54,268.04

Introducing Bonnie Douglas



I have nearly 30 years of experience in business, primarily in IT system/software development and project management. In Australia, I worked for Australia Post for 8 years, doing mathematical modelling of the parcels and letters networks to support network improvements. This involved a lot of business case development and support. In 2009 I was invited to join a start-up commercial mathematics company, Biarri.

I spent several years working with customers to deliver customised web-enabled algorithms and associated software that solved a variety of business problems, largely in logistics. The work was intellectually challenging, yet spiritually unfulfilling, and I decided I needed a change.

Last year I completed a Graduate Diploma in Counselling, and purchased a Curves gym in Mornington to keep myself amused, and because I

am a firm believer about the benefits of Curves for women's fitness and health. When I learned about a part-time Fundraising position at Polio Australia, it seemed like a good opportunity to use my business experience to support a great organisation.

Having attended the recent AGM and a Mornington Peninsula Post-Polio Support Group meeting, I am struck by the high levels of resilience and emotional strength held by the polio survivors I have met. I was also shocked to hear how some health professionals have dismissed assertions by people that they are suffering from the Late Effects of Polio, and that polio can't possibly affect anyone anymore because it has been eradicated (mostly). Polio survivors may be a small segment of the population, but are no less important than anyone else! I am so very excited to be able to support such an amazing organisation and group of people!

I am really looking forward to supporting Polio Australia through fundraising, and hope to support development of a long term strategic and financial plan to support the organisation well into the future. I look forward to meeting and interacting with you over the coming year! 🌟

Walk With Me Pictorial



*Walk With Me Brisbane
16 September 2017*



Walk With Me Canberra—30 November 2017

Breathe Fundraiser



Gary Newton

Polio Australia, with the help of Village Cinemas, was fortunate to secure the rights to 2 exclusive early-release screenings of the highly acclaimed movie *Breathe*, a real-life story of tragedy and resilience. Polio Australia ran the screenings of *Breathe*, starring Andrew Garfield (*Hacksaw Ridge*) and Claire Foy (*The Crown*), in Geelong and Melbourne during November and raised almost \$8,000 from the two events.

Polio Australia thanks Independent Board Member, Gary Newton, for all his work in negotiating the two screenings—especially in his home town of Geelong, which attracted 100+ people. Gary was also able to secure sponsorship from a number of organisations, as well as donations from individuals who were unable to attend; they are warmly acknowledged and thanked as follows:

*APCO Service Stations
Delia Bradshaw
Buxton Real Estate
GPPI
Jan McDonald
Rotary Club of Geelong East
Trudy Scholtz
Yellow Brick Road Geelong
Raffles and donation box takings*

Breathe: The Movie



Andrew Garfield talks about playing an inspiring, polio-stricken adventurer in "Breathe"

Source: inquirer.net – 20 November 2017

Taking his hero role a notch higher, Andrew Garfield champions the severely disabled in his latest sweeping romantic film opposite Claire Foy in "Breathe" – the true story of a couple truly in love as they refuse to be imprisoned amidst a devastating disease, dazzling others with their humour, courage and lust for life.

"Breathe" is a heart-warming and highly emotional celebration of bravery and human possibility, a love story about living every breath as though it's your last. Andrew Garfield vividly recalls reading the script of Breathe for the first time:

"I was on my travels, and I was told they needed an answer very soon. When I read it, I cried so much, I fell in love with it. I was so moved by the story. It felt like a road map of how to live, in terms of following the footsteps of Robin and Diana. 'How do you live a life of joy with the hand that fate deals you?' That's what it felt like to me. I was deeply moved by it. It answers the question: 'how do you live your life?' And there's

this whole issue of choosing joy in your life above all other ways, no matter what. I found that very inspiring".

"There's something humble about this story, which I like. There's nothing grandiose about it, it's just people getting on with their lives and living as fully as possible", concludes Garfield.

"Breathe" producer Jonathan Cavendish had always believed that his father's life story would be powerful material for a compelling film. Robin Cavendish (Garfield) had been a trailblazer, a remarkable, larger-than-life figure. He was diagnosed with polio in his late 20s and remained paralysed from the neck down. Totally reliant on a respirator that 'breathed' for him, he faced a life confined to a hospital bed. Yet he refused to accept that fate: with the help of his wife Diana (Foy), and their inventive and supportive friends, he found a way to live his life in the world, outside of hospital.

The couple's wanderlust remains as strong as ever. In order for Robin to travel, an old Bedford van is adapted so his wheelchair can fit in the passenger seat. With a new zest for life, he admits he always wanted to see the sunrise over the Mediterranean. Diana organises the trip, including travelling with racehorses aboard a transport plane to carry the family and their van to Spain. Despite a nail-biting incident when the respirator burns out, it's an idyllic experience for them all. Having already survived beyond the point his doctors expected, Robin wants to forge ahead and help other severely disabled people. He secures financing for more wheelchairs like his own to be built, and attends a conference in Germany where experts on severe disability are astonished by what he has already achieved.

Against all odds, Robin's severe illness has given him a new purpose in life – fighting tirelessly for the rights of disabled people. Diana and Robin's love for one another imbues their pioneering adventures with purpose, joy and laughter.

Read full article [here](#). 🌐



"Breathe" will be screening in Australian cinemas from 26 December 2017

Polio Eradication Unites The Australian Parliament



By Marny Cunningham

Source: www.globalcitizen.org / Advocacy Health – 26 October 2017

Whilst we rarely see politicians agreeing on an issue, this year's World Polio Day commemorations at Australia's Parliament House saw all Parliamentarians come together to throw their support behind eradicating polio once and for all!

The fact that polio is 99.9 percent eradicated is proof that vaccines work and that if we work together preventable diseases will be a thing of the past.

Global Citizen Australia joined forces with the Parliamentary Friends of UNICEF, RESULTS Australia, Rotary International, **Polio Australia** and UNICEF Australia to hold an event in acknowledgement of efforts to date and the task ahead to finally see polio eradicated from the world.

This year's event was especially exciting as we thanked (on behalf of the thousands of global citizens who took action calling for the Australian Government to make a further commitment to polio eradication) Australia's Minister for Foreign Affairs Julie Bishop and Minister for Health and Sport Greg Hunt for the \$18 million over two years commitment to the Global Polio Eradication Initiative (GPEI) ensuring ongoing support for this life-saving program.

Cross-party support for ending polio was truly demonstrated at the event when both Minister Hunt and Shadow Minister for Health Catherine King renewed the Coalition and Opposition's support for eradicating the preventable disease.

The Co-Chairs of the Parliamentary Friends of UNICEF Nationals' MP Andrew Broad (the Federal Member for Mallee) and Labor MP Senator Lisa Singh (Senator for Tasmania) spoke on behalf of the more than thirty One Last Push Parliamentary Champions in attendance confirming their strong support to ensure Australia continues to play a leading role in seeing this disease eradicated.

The event was moderated by Catherine McGrath former Bureau Chief and Chief Political Correspondent for SBS television who remarked on the how far the campaign to end polio has come since Rotary championed the efforts to rid the world of the awful disease over 30 years ago.

Alongside Maree Nutt CEO of RESULTS Australia, Trish Daley Board Director at Global Citizen Australia, and Noel Trevaskis Director of Rotary International, **polio survivor Rohan Clark from Polio Australia shared his personal experience of contracting polio as a child in primary school.** He opened up about how the disease still, and always will, affect his life.

"I need to lie down for half an hour every 4 to 6 hours. I rested before I came here, and I will rest again as soon as I finish here. As an adult I will be impacted by the disease for my entire life", Clark shared with attendees.

Read more: [Australia Gives \\$450,000 to Polio Survivors Group](#)

The event wrapped up with a call to action from Global Citizen's Australian Country Director Sarah Meredith asking everyone to call on the Australian Government to do their part in the fight against preventable diseases like polio by ensuring it is put on the agenda at next year's Commonwealth Summit in London.

Full article [here](#). 🌐

Mobility Scooters—Not Another Enquiry!

Source: Scooters Australia Media Release
– 7 December 2017

Leading mobility scooter importer and retailer, Scooters Australia, welcomes the probe into the mobility scooter industry by the Rural and Regional Affairs and Transport References Committee, announced recently.

The enquiry has been spearheaded by Senator John Williams, since his wife was involved in an accident with a mobility scooter and injured her hip.

Managing Director of Scooters Australia, Peter Fraser, said that the safety issue of mobility scooters might be settled once and for all if the committee investigates the issue thoroughly.

"Australia already has some of the strictest regulations regarding mobility scooters in the world and if the committee is serious about looking at international practices, the mobility scooter industry has nothing to hide", said Mr Fraser.

"Mr Williams has admitted that over a ten year period from 2000 to 2010 only sixty-two people had died as a result of incidents involving mobility scooters. That's less than one per state per year for a mobility product that gives untold thousands of people independence and freedom when they might otherwise be housebound", he said.

According to Mr Fraser, the biggest problem with scooter safety is the appalling lack of infrastructure for anything other than motor cars in Australia.

"There has been a consistent lack of attention to providing better footpaths, cycle paths, and facilities for mobility scooters, bicycles and pedestrians all over Australia, and particularly in regional cities and towns where mobility scooter users often have to travel on the edge of the road because there are no footpaths", he said.

"Mr Williams' wife was injured in a country town and my own in-laws cannot use a mobility scooter in their coastal town because of the lack of footpaths", said Mr Fraser.

"Instead of wasting yet more money on an enquiry, the Federal government should be paying a lot more attention to what the rest of the world is doing in providing decent infrastructure for people who use mobility scooters to get around their community", he said.

"Mobility scooters already have the best, the safest, record which will only improve with better footpaths to accommodate the inevitable increase in popularity of this form of local transport", he said.

More information: peter@scootersaus.com.au 



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Better Health Care For People With Chronic Conditions



Source: Media Release – 1 December 2017

*The Hon Greg Hunt MP
Minister for Health
Minister for Sport*

Up to 65,000 Australians will soon be receiving improved care for their ongoing chronic conditions, with the expansion of the Australian Government's trial of Health Care Homes.

An additional 168 general practices and Aboriginal Community Controlled Health Services (ACCHS) will offer Health Care Home services from today, building on the 22 clinics already in the trial.

Additional practices are expected to sign on in the coming weeks.

Patients with two or more chronic conditions – such as diabetes, arthritis and heart and lung conditions – are eligible to enrol at a Health Care Home to receive integrated, team-based care.

Each Health Care Home patient will have their own care team, which may include their GP, a practice nurse, their specialist, physiotherapist, dietician and pharmacist.

This type of care puts the patients' needs and goals first, and helps them take more control in managing their health.

Rather than treating problems as they arise, the focus of Health Care Homes is on helping patients to stay as well as possible and avoid having to go to hospital.

Health Care Homes will receive a monthly payment from the Government for providing care to each patient, instead of the usual Medicare payment for each service.

Enrolment of patients will occur over the next 12 months, as practices adjust their processes and business systems for the Health Care Homes model.

This trial of Health Care Homes is a key part of the Turnbull Government's plans to strengthen Medicare and improve the effectiveness of primary health care, including chronic disease management and prevention.

One in every two Australians now has a chronic health condition, and one in four has two or more chronic health conditions. This is creating a major burden on individuals and families as well as the health system.

The Health Care Home trial builds on the high quality care services already provided by many general practices and ACCHS for people with debilitating long term conditions.

The Health Care Homes participating in the trial are located in the following regions:

- Perth North
- Northern Territory
- Brisbane North
- Nepean Blue Mountains
- Western Sydney
- Hunter, New England and Central Coast
- South Eastern Melbourne
- Tasmania
- Country South Australia
- Adelaide

For more information visit the [Department of Health's website](#).

New Era For Diversity In Aged Care

Source: [Media Release](#) – 06 December 2017

*The Hon Ken Wyatt AM MP
Minister for Aged Care*

The Turnbull Government has today released Australia's latest Aged Care Diversity Framework, signalling a new, more inclusive era in aged care.

The Minister for Aged Care, Ken Wyatt AM, said all seniors in Australia – no matter what their background, location or life experience – should receive aged care services that suit their individual needs.

"This is part of our focus on customer engagement through the personalisation of services, not for the majority of seniors in our communities, but for everyone", Minister Wyatt said.

"This Framework will help the aged care sector identify what it can do to drive cultural and systemic improvements that take into account our diverse population. Any one person can belong to any number of diverse groups, which is why we have to focus on understanding and addressing individual needs".

The Framework's six priority areas are:

- Making informed choices
- Adopting systemic approaches to planning and implementation
- Accessible care and support
- Supporting a proactive and flexible system

- Respectful and inclusive services
- Meeting the needs of the most vulnerable

Minister Wyatt said the new Framework would also support the more than 36 per cent of seniors who were born outside of Australia.

"We know from experience that when some people who were born overseas grow older, they can revert back to using their mother tongue, which can be a challenge in aged care", Minister Wyatt said.

"This Framework acknowledges this and will assist in ensuring these people receive the aged care they deserve".

An Aged Care Sector Committee Diversity Sub-Group produced the Framework after broad community consultation.

"I thank all the members of the sub-group for their hard work and dedication", said Minister Wyatt.

"The Framework is intended to be used by all governments with responsibility for aged care policy and programs, peak organisations and aged care service providers".

Under the Framework, three action plans will be developed in the first half of 2018, to target particular barriers and challenges faced by Aboriginal and Torres Strait Islander people, CALD communities, and people who identify as LGBTI.

The Framework is available on the [Department of Health's website](#). ●



This photo was sent to Polio Australia by Bill Peacock, taken at his Bribie Island medical clinic. It features Polio Australia's "The Late Effects of Polio: Do you know the signs" flyer.

Advise your medical clinic that this flyer can be downloaded from Polio Australia's website here: www.poliohealth.org.au/recognise-the-signs

Together, we can help more polio survivors and health practitioners understand the Late Effects of Polio.

Codeine Crackdown

By Debbie Schipp@debbieschipp

Source: [news.com.au](https://www.news.com.au) – 15 September 2017

YOU won't be able to buy Nurofen Plus, Codral or Panadeine with a simple trip to the chemist next year, and pharmacists aren't happy about it.

A CODEINE crackdown which will see common pain medications require a prescription won't end abuse of the drug, and will make it even harder to track.

That's the claim from the Pharmacy Guild of Australia, which says making products like Nurofen Plus, Panadeine, Mersyndol and Codral available only with a prescription next year will lead to an increase in 'doctor shopping'.

The changes on February 1, 2018 will see codeine products 'upscheduled', meaning people who use the products for health issues like back pain, migraines, period pain, dental pain or cold and flu will have to go to the doctor to get access to them.

The Therapeutic Goods Administration (TGA) made the decision last year because consumers frequently became addicted to codeine.

And while the Australian Pharmacy Guild is on board with an education campaign advising consumers of the changes, it maintains upscheduling is an unnecessary headache.

It says a system in place in many pharmacies for almost two years has already seen a drop in use, and detecting who may be abusing codeine better than doctors' surgeries and medical centres can.

The Guild is currently lobbying individual State and Territory governments for exceptions to the scheduling restriction, which would mean pharmacists could continue to dispense the products, with a number of conditions and restrictions, national president George Tambassis said.

Codeine will no longer be available over the counter and will need a prescription from a chemist after February, 2018.

"Under our plan, codeine will still go prescription only, but there will be exceptions which would allow pharmacists to supply", he said.

Those conditions would include the medication could be used for acute, rather than chronic pain, and be sold in very small quantities, and their supply would be marked in a real-time recording system.

The plan being put to State governments would make use of the MedsASSIST monitoring system



Picture: Katrina Bridgeford

already in place in many pharmacies, Mr Tambassis said.

The program, developed by the Guild, is a monitoring system which identifies and supports patients who may be misusing codeine containing over-the-counter analgesics, he said.

It requires customers buying the medications to provide a drivers licence, similar to what is required of customers buying products containing pseudoephedrine, ahead of purchase.

"The programs links the participating pharmacies. As soon as you give your driver's licence, your history pops up on the computer — regardless of which pharmacy you've been to", Tambassis said.

"If it shows customers are using the medication wrongly or too frequently, it's a tool to alert us, and allow us to start a discussion with you". We have had that for almost two years now, but unfortunately no government has asked for it to become mandatory".

He says about 70 per cent of community pharmacies are using MedsASSIST and there's been a drop of 20 per cent in the sale of codeine-containing medications in that time.

"We believe the mandatory recording system is the best way to limit the sale of those drugs", he said.

"DOCTORS CAN'T DO THIS"

The Guild believes the prescription-only rule won't stem codeine abuse, because doctors don't use a national tracking system which would highlight misuse.

"We fear doctor shopping. The doctor has no way of knowing — other than a patient's word — if the codeine they are being asked to prescribe was recently prescribed by another doctor", he said. There is no medical centre anywhere in Australia that has anything near what we have with MedsASSIST".

(cont'd P15)

Codeine Crackdown *(cont'd from P14)*

"And there's been no proactive action taken by any doctor groups to put in place a real time recording and monitoring tool to help identify patient misuse. Not only will doctors be swamped when this changes in February, but this is a professional slap in the face for pharmacists".

The Guild believes patients using these medicines should still have access without a prescription.

"We want to maintain safe and convenient access to those using these medicines safely and appropriately, while putting extra safeguards in place", Mr Tambassis said.

"What our opponents on this issue are saying is they want to remove convenient access for consumers. They want to put no safeguards in place except for a prescription".

WHY THE CHANGE?

Doctors groups including the Australian Medical Association support the prescription-only plan.

The Therapeutic Goods Administration's move to limit supply to prescription-only followed the lead of the US, most of Europe, Hong Kong and Japan.

All those countries stopped the sale of codeine products without a script after studying evidence of the harm caused by their overuse and abuse.

"Low-dose codeine-containing medicines are not intended to treat long-term conditions, however, public consultation indicated that many consumers used these products to self-treat chronic pain", the TGA said as it announced the change.

"This meant that consumers frequently became addicted to codeine. The TGA decision maker also took into consideration that there is little evidence that low-dose codeine medicines are any more effective for pain relief or cough than similar medicines without codeine".

The decision came after reports codeine addicts were swallowing up to 100 tablets a day, and people were "pharmacist shopping" to get around rules restricting purchases of more than five days' supply of the drug at one time.

Companies who make the products have had mixed reaction to the up-scheduling.

The maker of Panadeine products, GlaxoSmithKline has ceased manufacturing those products, declaring it will pull them from Australia.

Other companies are believed to be reformulating popular brands by removing the codeine so they can still be bought over the counter.

As the upscheduling looms, the Guild and peak pharmacy body, the Pharmaceutical Society of Australia (PSA), have welcomed Federal government funding to ease the changeover via pharmacist education and a public education campaign.

It's estimated the change will affect about one million patients.

Go to the [NPS Medicinewise](#) website for more information.

Painaustralia on Codeine Rescheduling

Source: [Painaustralia Newsletter](#)

—October 2017

Painaustralia has joined with key health groups urging state and territory governments and federal parliamentarians to support Australia's medicine regulator, the Therapeutic Goods Administration (TGA), in its decision to make codeine-based medications available only with a prescription from February 2018.

Joining the Rural Doctors Association of Australia (RDAA), Royal Australian College of General Practitioners (RACGP), Royal Australasian College of Physicians (RACP) and Consumers Health Forum (CHF), Painaustralia signed an [open letter](#) to state and territory health ministers warning that any changes or exceptions to complying with the TGA's legislation will put health and lives at risk.

Previously in a joint [media release](#) with the RACP and the RACGP, Painaustralia called for appropriate pain management to be given higher priority, particularly in rural locations where reliance on opioids is a significant issue and access to pain services is limited.

This week, Painaustralia also joined with the RACP, RDAA, CHF, as well as the Faculty of Pain Medicine and The Society of Hospital Pharmacists of Australia in a joint letter to all Federal Members of Parliament and Senators to reiterate the importance of respecting the integrity of the TGA's decision and call for better access to more effective pain management options. Painaustralia's recent fact sheet and infographic on codeine was also sent to the parliamentarians.

(cont'd P16)

Painaustralia on Codeine Rescheduling *(cont'd from P15)*

Carol Bennett Painaustralia CEO says, "*Chronic pain is a major health issue in Australia. We need to do much better than offering medications that are often both ineffective and potentially harmful in responding to chronic pain.*"

Doing her part to communicate the message, in an [interview for Sydney's Channel 9 News](#) and also [ABC News 24](#) Ms Bennett detailed the improvements we need in pain services and why opioids are not the answer to chronic pain management while useful for acute forms of pain. She also explained to [News Corp National Health Reporter Sue Dunlevy](#) why Australia needs a coordinated pain management strategy. [An article](#) by Painaustralia Board Member Associate Professor Malcolm Hogg published today in *Croakey* also explains the value of multidisciplinary pain management.

Studies show people with unmanaged or poorly managed chronic pain are a major group at risk of drug dependence and misuse, as well as accidental overdose. Chronic pain has been implicated in more than one in three (35.8%) codeine-related deaths, with codeine-related deaths more than doubling between 2000 and 2009. This is despite evidence showing it is not effective for the treatment of long-term pain.

Codeine is a poor analgesic when compared to other over-the-counter (OTC) pain medication and the low doses of codeine added to OTC preparations are not high enough to provide benefit, yet they add to the risk of potentially harmful side-effects. Our latest [codeine fact sheet](#) and [codeine infographic](#) are useful explainers on this issue. ●

Clinical Signs Accurately Identify Pneumonia

By Jennifer Garcia

Source: Medscape – 29 November 2017

Four clinical variables — the presence of fever, elevated pulse rate, crackles on auscultation, and low oxygen saturation — can help identify patients with pneumonia in the primary care setting, according to new data.

"[T]he four variables identified by this analysis are easily measured clinical signs", write Michael Moore, BM BS, MRCP, FRCGP, from the University of Southampton, Aldermoor Health Centre, United Kingdom, and colleagues.

"If antibiotic prescribing was restricted to people who had one or more of these signs, it could substantially reduce antibiotic prescribing for this condition", the authors write in an article [published online](#) November 22 in the *European Respiratory Journal*.

For the prospective cohort study, the researchers evaluated 28,883 patients between 2009 and 2013 who presented to their primary care provider with symptoms of acute cough attributed to a lower respiratory tract infection.

Among the 720 patients radiographed within the first week after their initial consultation, 16% (115/720) were diagnosed as having definite or probable pneumonia.

The researchers noted specific independent predictors of radiograph-confirmed pneumonia among this cohort, including temperature 37.8°C or higher (risk ratio [RR], 2.65; 95% confidence interval [CI], 1.46 - 4.81), pulse rate 100/minute or higher (RR, 1.90; 95% CI, 1.12 - 3.24), crackles on auscultation (RR, 1.82; 95% CI, 1.12

- 2.97), and oxygen saturation below 95% (RR, 1.73; 95% CI, 0.98 - 3.06).

Overall, 86.1% (99/115) of patients with pneumonia exhibited at least one of these clinical signs. In contrast, other factors, including presenting symptoms, age, sex, smoking history, and past medical history, provided no predictive information for a pneumonia diagnosis.

The authors note that previous studies have found fever, crackles, and elevated pulse rate to be predictors for the presence of pneumonia. However, unlike the current best diagnostic model, the presence of a runny nose was not found to be significant in the present study. In contrast, the addition of pulse oximetry has demonstrated clinical utility in previous retrospective studies in the primary care setting.

The researchers acknowledge limitations to the study, primarily that thoracic radiographs were only obtained in a small sample of the full cohort and that those patients selected for radiography were more ill and at higher risk for pneumonia. This may have resulted in fewer reported cases of radiograph-confirmed pneumonia in the cohort as a whole, and as well as overemphasis of the importance of the four clinical signs as positive predictors of pneumonia.

Given this limitation, the study authors caution that, although pulse oximetry may have a role in the diagnosis of pneumonia, further studies that include comprehensive assessment, including thoracic radiographs, will be required.

Eur Respir J. Published online November 22, 2017. [Full text](#) ●

The Last Of The Iron Lungs

By [Jennings Brown](#)

Source: gizmodo.com – 20 November 2017

Martha Lillard spends half of every day with her body encapsulated in a half-century old machine that forces her to breathe. Only her head sticks out of the end of the antique iron lung. On the other end, a motorized lever pulls the leather bellows, creating negative pressure that induces her lungs to suck in air.

In 2013, the Post-Polio Health International (PHI) organization estimated that there were six to eight iron lung users in the United States. This fall, I met three polio survivors who depend on iron lungs. They are among the last few, possibly the last three.

Their locations form a line that cuts directly through the heart of the country—one in Dallas, one outside Oklahoma City, and one in Kansas City, Missouri—what some call tornado alley.

Storms have always been especially difficult for Lillard because if the iron lung loses power, she could die in her sleep. She lives alone, aside from three dogs and 20 geckos that she keeps in plastic terrariums filled with foliage and wool. *"They like to sleep in the fleece, wrapped up like a burrito"*, she said as she introduced me to a few of her favorites.

Lillard sleeps in the iron lung, so it is in her bedroom. Even though the tank is a dull canary yellow it pops in the room, which is painted chartreuse—like the rest of the house, inside and out—and filled with toys and dolls that she has collected throughout her lifetime. On the walls hang a crucifix, a plush Pink Panther, and mirrors strategically placed so she can see around the room and into the hallway.

Her iron lung has portholes and windows on the side; a pressure gauge at the top. The machine is actually cobbled together from two iron lungs. One, the March of Dimes gave her when she was a child. The other, she bought from someone in Utah, after she haggled him down from \$25,000 to \$8,000. The body has also been modified over the years. Her grandfather invented a motorized pulley system that closes the bed tray into the tank after she climbs in. He also replaced the brushed aluminum mirror above the neck slot with a real mirror so that she could have a clear view to the rest of the room when she's locked in the canister. A local engineer used a motor from an old voter registration device to build a mechanism that tightens the collar around her neck after she slips her head through the portal. The fan belts and half-horsepower motor have been replaced about ten times.

"It seemed like forever because you weren't breathing. You just laid there and you could feel



Martha Lillard inside her iron lung, which has been modified by mechanics over the years. Photo: Jennings Brown for Gizmodo

your heart beating".

When Lillard is outside of the tank, she can breathe using a positive-pressure ventilator, a smaller device that pushes air into her lungs. But that instrument doesn't provide the same relief as when she puts her entire body into the 640-pound, 7-and-a-half-foot-long apparatus. Plus forcing air into the lungs can cause inflammation or damage the air sacs. When she's sick, she can only heal if she spends full days in the iron lung. She calls herself 'a human battery' because she has to recharge every day.

Lillard is 69, 4-foot-9 and weighs 98 pounds. Her back is arched from scoliosis. She didn't get surgery when she was a child because doctors didn't expect her to make it to her teenage years and she never had an operation as an adult because polio survivors can stop breathing when they're on anesthesia.

She was infected with polio at her 5th birthday party at the Joyland Amusement Park on June 8th, 1953. Nine days later, her neck ached so bad she couldn't raise her head off the pillow. Her parents said it was probably just a summer cold, but Lillard could tell they were afraid. They took her in for a spinal tap, which confirmed it was polio.

Lillard asked me to take out a photo album so she could show me snapshots of her youth as she sat on a blanket on the floor of her living room, where it's more comfortable for her to sit when she's out of the machine. *"I wanted to be a ballerina. That was my big wish. I started walking on my toes when I was one, and I just constantly was after ballerina dolls. We didn't have a dance school in town until I was five and my mom was going to enrol me that year, but I got sick"*, she told me. *"I think now of my life as a ballet. I have to balance so many things. It's a phenomenal amount of energy I have to use to coordinate everything in my life"*.

Read the full article [here](#). 🌟

How A Polio Survivor Became An Ironman World Champion

By Alexandra Klausner

Source: [New York Post](#) – 26 September 2017



When she was 6 months old, Minda Dentler was paralyzed from the waist down by polio and abandoned by her mother at an orphanage in Mumbai, India. She wasn't expected to live past her 18th birthday — let alone become the first female wheelchair athlete to complete the Ironman World Championship.

The 39-year-old mother, motivational speaker and insurance executive, who lives in New York City,

has completed 30 triathlons, including four Ironmans. Her next major goal is to break her 13:07 Ironman record at an upcoming race in Florida in November.

"I would say to anyone with or without disabilities, it is better to be in the game or on

the court than to be on the sidelines", she told The Post.

Dentler — who has paralysis in both legs — is unable to walk without the assistance of leg braces and crutches, and uses a wheelchair in her day-to-day life.

Dentler, who was adopted by a family in Spokane, Washington, when she was 3½ years old, credits her adoptive parents with helping her get surgeries on her hips, legs and back, which straightened her body and gave her more mobility.

Spending her childhood paralyzed from the waist down was just one of the many challenges she faced after coming to America.

She said one of the greatest joys she has felt as a mom was watching her daughter get vaccinated for the first time — a health benefit she never received as a baby in India.

"As a person who has been affected by a preventable disease, I have become an advocate for global childhood immunization and polio eradication", she said.

Full article [here](#). 🌟

Meet The Indian Polio Survivor and Video Model

By Disha Roy Choudhury

Source: [IndiaToday.in](#) – 7 December 2017

Mahalakshmi Mahadev is a 26-year-old engineering graduate from Bengaluru. She is also a polio survivor, who has broken new grounds by modelling for a video advertisement.

Recently, Mahadev featured in a 44-second advertisement for a clothing line. In the video, she is seen posing in colourful ensembles. It is only when you watch the video till the end that you find her being placed on a wheelchair.

Mahadev had to undergo a 13-hour-long shoot in Chennai, for Visakan's label for designer wear and adaptive clothing for the differently abled. *"I was nervous first, now I'm so happy. The differently abled can do anything. If they dream, they can achieve it. It's important our advertisements turn inclusive",* she was quoted as saying by NDTV. Mahadev also shared the video on social media and thanked people for their support.

Initially, Visakan and her differently abled entrepreneur and husband, Visakan Rajendiran, could not find anyone who would be interested in featuring a differently abled person as a model. *"No one was coming forward to feature a differently abled person as a model. We did not*



Picture courtesy: Facebook/Surae Srendiran

want to sit and complain about it. So we did one for our own brand", said Visakan.

Later, the team shot the video with Mahadev, along with cinematographer Jerald Dinesh and make-up artist Suresh Menon, who offered their respective services free of cost.

"It was an interesting concept. Mahalakshmi was very cooperative. No one would have known she's differently abled. But we showed her on a wheelchair at the end, to motivate others", Dinesh was quoted as saying.

Click [here](#) for video. 🌟

Life With Polio: Adil's Story

Source: polioeradication.org
—1 December 2017

Nine-year old Adil Khan comes from Peshawar, Pakistan's sixth largest city and capital of Khyber Pakhtunkhwa province. He is the oldest of the four children of Shami Ullah, a local laborer who often struggles to make ends meet. Together with his wife and four children, he lives in Wahid Ghari, a poor area of Peshawar, where many other underprivileged families reside.

If Shami Ullah's life wasn't difficult enough already, Adil was diagnosed with polio in 2008, only 5 months after he was born. After a couple of days of high fever followed by weakness in his left leg, Shami Ullah rushed his baby to the hospital where Adil was tested for polio. Unfortunately, the test came back positive. *"We had heard about polio before, so when we learnt our son had it, we were very worried",* Shami Ullah said. *"I just didn't want to accept that Adil would not be able to walk his entire life".*

Adil's story is not unique. In 2008, 21 children in Peshawar were diagnosed with polio, while there were a total of 117 cases reported that year in Pakistan. So far this year, there have been only five cases of wild poliovirus reported in Pakistan, down from 20 last year and 54 in 2015. The recent progress has been the result of strong government commitment, support and oversight at every level, strengthened programme performance and broad community acceptance.

Polio is a crippling and potentially deadly infectious disease caused by the virus which invades the nervous system and can cause irreversible paralysis. For polio victims, this has often meant lifelong social exclusion. However, Adil can walk and goes to school, thanks to the support of orthotic devices and physiotherapy. *"We are so happy to see our eldest son run. He is just like other children",* Adil's father said.

The rehabilitation story of Adil is one of almost 700 stories of children who have been provided with rehabilitation services by Pakistan's Polio Rehabilitation Initiative. The initiative, which started in 2007, initially provided support to children from Pakistan's province of Khyber Pakhtunkhwa and Federally Administered Tribal Areas. In November 2011, the programme increased its span to almost all parts of Pakistan.



Adil Khan is getting his orthotic device replaced at PIPOS, Peshawar
©NEOC/PAK2017/Faran Tanveer

"This initiative of provision of rehabilitation services to polio affected children is an important combination of medical and social rehabilitation", said Dr Maryam Mallick who heads the Polio Rehabilitation Initiative with WHO Pakistan.

When a child is paralyzed with polio, a rehabilitation officer visits the home of the polio patient to assess the needs. On the basis of this assessment, rehabilitation plans for both medical and social rehabilitation are being developed. The medical services include provision of orthotic devices, surgical procedures, physiotherapy, as well as regular follow-up services.

There are many benefits to rehabilitation to these children – with the right treatment children not only improve mobility, but they gain independence and allow them to enrol in school.

"To ensure the regular attendance of the child, the educational expenses for the yearly tuition fee, uniform, books, shoes, and even a small amount for pocket money is being given to the principal of the respective school instead of being given to the parents", Dr Mallick said.

Adil is currently a second grade student at the Peshawar Cambridge Public School. He likes to study, which makes his father proud. *"When he grows up, I would like him to become a doctor so that he can help people in need",* said Shami Ullah, who is also now a strong advocate of the Polio Eradication Initiative. 🌟

Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 6 December 2017

Amidst conflict and humanitarian crisis in Syria, health workers are battling to end the current polio outbreak. Since the World Health Organization announced the outbreak on 8 June 2017, 70 cases have been confirmed, with 67 in Deir Ez-Zor governorate, two in Raqqa and one in Homs. In order to reduce the threat of polio spreading to the countries surrounding Syria, vaccination activities have been carried out in Iraq, Lebanon and Turkey. These activities are aiming to reach both Syrian children and those from local communities to limit the possibility for the virus to spread across international borders.

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	16	80	34	3	37	5
—In Endemic Countries	16	0	34	0	37	2
—In Non-Endemic Countries	0	80	0	3	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	11	0	12	0	13	0	5 Nov 2017	N/A
Democratic Republic Of The Congo	0	10	0	0	0	0	N/A	17 Sep 2017
Lao People's Democratic Republic	0	0	0	3	0	3	N/A	11 Jan 2016
Nigeria	0	0	4	0	4	1	21 Aug 2016	28 Oct 2016
Pakistan	5	0	18	0	20	1	21 Aug 2017	17 Dec 2016
Syrian Arab Republic	0	70	0	0	0	0	N/A	9 Sep 2017

