

# POLIO NSW

formerly Post-Polio Network (NSW)

# NETWORK NEWS

## Incorporating – Polio Oz News

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## President's Corner

Gillian Thomas

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

Gillian Thomas	<i>President</i>	Nola Buck
Susan Ellis	<i>Vice-President</i>	Ella Gaffney
Merle Thompson	<i>Secretary</i>	Chris Keun
Alan Cameron	<i>Treasurer</i>	Janette McKenzie
Charles Anderson		Diana O'Reilly
Anne Buchanan		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/](http://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/](http://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.

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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.

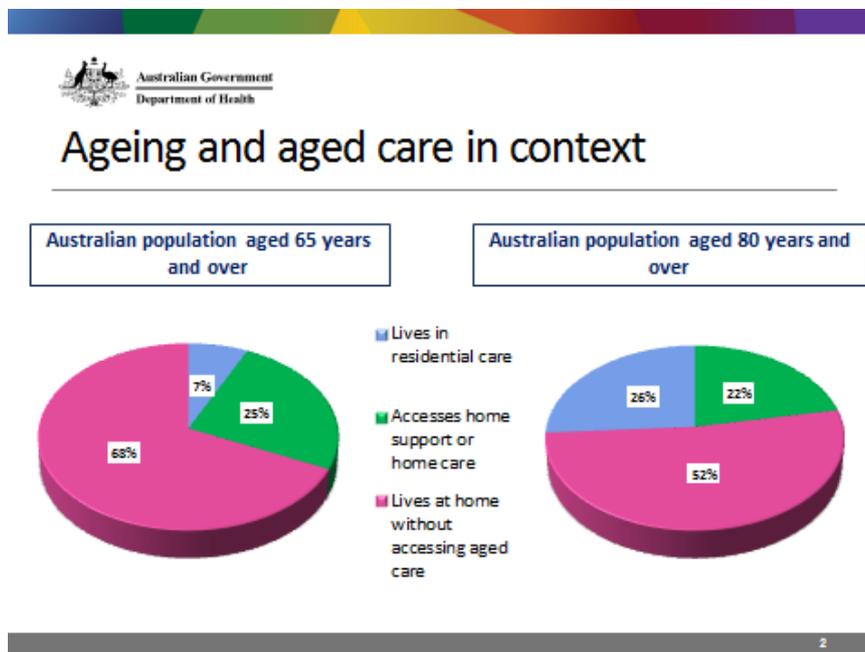
Polio Australia has since created a Health Professionals Register of skilled and knowledgeable ‘post-polio’ practitioners across many different modalities around Sydney.

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, 27<sup>th</sup> 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](http://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](http://www.myagedcare.gov.au)>.

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

Australian Government | **myagedcare**

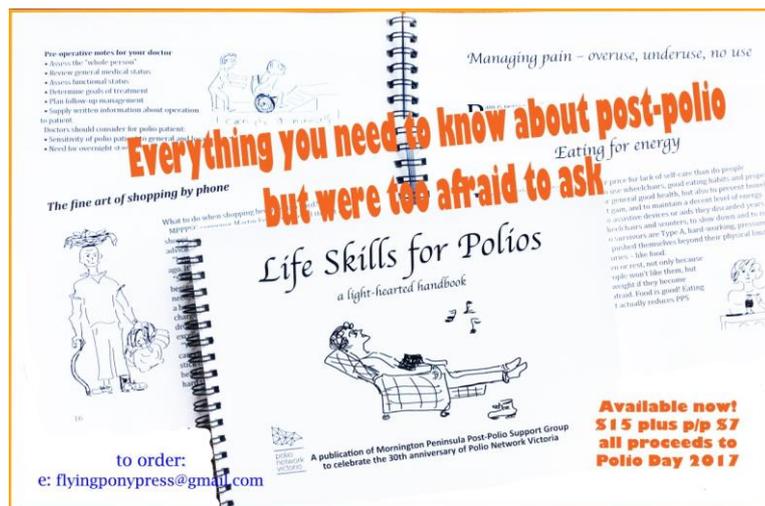
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# Life Skills for Polios - a light hearted handbook



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,

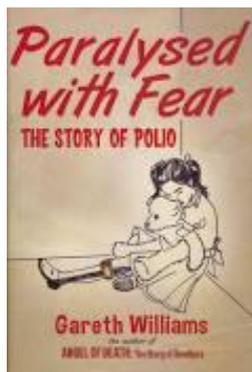
author and polio survivor Fran Henke, in themes of Home, Body and Mind – covering downsizing, tips for the kitchen and laundry, plus the big topics of pain, fatigue, exercise, and coping with past treatment in the face of the new symptoms.

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](mailto: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](mailto: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](http://www.jennermuseum.com)>.

[Editor’s note: This book is also available from online bookstores in Australia, such as <[www.fishpond.com.au](http://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 20<sup>th</sup> 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.)

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Contact the e-Bility team to upcycle and turn your disused equipment into cash and a clean and clutter free space!

[www.e-bility.com](http://www.e-bility.com)      1800 029 904      email: [sales@e-bility.com](mailto: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](http://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](mailto: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](mailto: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](http://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](http://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/](http://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 3<sup>rd</sup> 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](http://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](mailto:disaware@bigpond.com)>  
Mobile: 0412 903 639 Phone: 02 9398 7820

## Management Committee - Executive Members Contact Details

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Nola Buck/Susan Ellis	Co-editors <i>Network News</i>	editor@polionsw.org.au	02 9890 0946

## Have You Included Your Polio Details on the Australian Polio Register?

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,850 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](http://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*