



# POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

# NETWORK NEWS



## Incorporating – Polio Oz News

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

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

**Patron: Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS**

### President's Corner

Gillian Thomas

Welcome to another combined issue of Network News and Polio Oz News.

Our **Mid-Year Seminar** will be held on **Wednesday, 23 July at the Northcott Building in Parramatta** – full details are on page 2. A **Seminar Registration Form** is enclosed – please be sure to **RSVP by Friday, 18 July** to ensure we cater sufficiently. There is a great line-up of speakers so you won't want to miss the opportunity to hear their presentations.

It is also **Membership Renewal** time. Enclosed, you will find one of two forms, depending on your financial status. If you are currently paid up to 30 June 2014 (*your address sheet reads Renewal Due On: 1/07/14*) you will find a Membership Renewal Form enclosed for the period 1 July 2014 to 30 June 2015. Could you please confirm, complete, or amend your details as given on the Form, and return it with your subscription to the Treasurer at the Polio NSW Parramatta postal address above. A growing number of members appreciate the ability to pay their membership subscription via internet banking. If you take up this option, please ensure your name is recorded on the payment and email the payment transaction details to <treasurer@polionsw.org.au>. Without this information it may be impossible for us to credit the payment to your membership.

There is still a number of people whose annual subscriptions are overdue, and so their address sheet reads *Renewal Due On: 1/07/13* (or earlier). In this case, the Membership Renewal Form covers more than one year's membership. We would appreciate prompt payment of the outstanding dues, together with the current dues, to ensure that you continue to receive your newsletter and other mail-outs. Polio NSW is self-funded and needs your continued support to enable us to keep providing services to polio survivors and their families.

If you are already financial beyond 30 June 2014 (*again as shown on your address sheet*), you will receive a **Membership Update Form** which gives your current details but does not request payment of a membership subscription. Please check your details and be sure to return the Form if any amendments are required.

Those members who came along to Polio Australia's inaugural participation in Northcott's Walk With Me fund-raising event last September had a great time. The good news is that the Walk is on again this year on Friday, 12 September. With donations received this year being split 50/50 between Polio Australia and Polio NSW, you can support not only Polio NSW but our national organisation. **Full details are on the "Walk With Me" website <www.walkwithme.org.au> – we look forward to walking with you!**

**This year Polio NSW celebrates 25 years of support for polio survivors in our State. We are holding a special anniversary lunch in conjunction with the Annual General Meeting and End-of-Year Seminar, on Saturday, 29 November 2014, at Burwood RSL Club. Further details will be in the next issue of Network News. Please be sure to put this date in diary now!**

Unless otherwise stated, the articles in Network News may be reprinted provided that they are reproduced in full (including any references) and the author, the source and Polio NSW Inc are acknowledged in full. Articles may not be edited or summarised without the prior written approval of Polio NSW. The views expressed in this publication are not necessarily those of Polio NSW, and any products, services or treatments described are not necessarily endorsed or recommended by Polio NSW.

# Mid-Year Seminar

**Date:** Wednesday, 23<sup>rd</sup> July 2014

**Time:** 9:30 am – 3:00 pm

**Venue:** Conference Room, Ground Floor, The Northcott Building  
1 Fennell Street, Parramatta

*A special arrangement has been made to enable members and friends attending the Seminar to park in the Parramatta Leagues Club car park, thanks to the generosity of the Club management. Simply tell the security person at the car park entrance in Grose Street that you are attending the Polio NSW Seminar in the Northcott Building, and please park in the right-hand back corner of the car park. You can then enter the Northcott Building via the gate into its adjacent playground.*

**Refreshments:** Morning tea and a light lunch will be provided  
(cost subsidised by Polio NSW)

**Cost:** \$10 per person – ***please RSVP by Friday, 18<sup>th</sup> July 2014***

*If possible, please return the **enclosed Registration Form** with your payment to the Polio NSW Office by 18<sup>th</sup> July. Otherwise, you can pay when you arrive at the Seminar, however, if you elect to do this, you MUST still contact the Office either by email, office@polionsw.org.au, or telephone 02 9890 0946 by Friday 18th July to confirm your attendance so sufficient catering can be arranged.*

---

**Program:** 9:30 *Registration*

10:00 **Ms Jenny Ly** – Senior Health Promotion Officer with Arthritis and Osteoporosis NSW – “*Complimentary Medicines and Health Education*”

11:00 *Morning Tea*

11:30 **Mr Robert McLeod** – CEO Sydney Cochlear Implant Centre - “*The Work of SCIC and the Cochlear Implant*”

12:30 *Lunch*

1:30 **Emeritus Professor Barry Baker** – Former Prof of Anaesthetics at Sydney University – “*The Part Polio Played in the Formation of Intensive Care Units and Current Management of Ageing Polio Patients Particularly During Surgery*”.

3:00 *Close*

***All are welcome – we look forward to catching up with everyone on 23rd July 2014***

## **Presenters:**

**Ms Jenny Ly** is currently the Senior Health Promotion Officer at Arthritis and Osteoporosis NSW. Her role involves educating groups in the community and is largely focused on the range on Healthy Lifestyle Programs for people with arthritis or osteoporosis. Jenny is a pharmacist by profession and has a special interest in complementary medicines and health education.

**Mr Robert McLeod** has had many years as a banking and finance executive. He has been six years with Sydney Cochlear Implant Centre (SCIC), the last four as Chief Executive. SCIC is the third largest cochlear implant programme in the world.

Robert has a 17 year old son who was born profoundly deaf and who has 2 cochlear implants. Robert said this is a special reason for his involvement with SCIC.

**Emeritus Professor Barry Baker** graduated MBBS from the University of Queensland in 1963 and doctor of philosophy (DPhil) from Magdalen College in the University of Oxford in 1971. He has specialist qualifications in anaesthesia (FANZCA and FRCA) and in intensive care. He was reader in Anaesthesia, University of Queensland 1972 to 1975. Foundation Professor of Anaesthesia and of Intensive Care, University of Otago 1975 to 1992, and Nuffield Professor of Anaesthetics, University of Sydney 1992 to 2005. He is currently the Dean of Education for the Australian and New Zealand College of Anaesthetists. We very thrilled to learn that Barry was awarded an AM in this year's Queen's Birthday Honours: "*For significant service to medicine, particularly to cardiovascular anaesthesia, to medical education, and to professional medical organisations*".

Barry also has a keen interest in the history of medicine. He has more than 200 publications in the academic and scientific literature on anaesthetic, physiological and historical topics.

---

## **For Sale**

Paul Galy was a presenter at the recent Polio Health and Wellness Retreat held at Baulkham Hills. Many of our members are familiar with Paul who is a Footwear Practitioner and orthotist. Paul has written a book called "**The 4<sup>th</sup> of May: The Memories of Paul Galy OAM**" which he discussed with us at the Retreat.

Born in Hungary, Paul was amongst the first Hungarian refugees to arrive in Australia after the Hungarian Revolution in 1956. He came from a long family line of corrective footwear manufacturers. The family business dates back at least to the early 1880s when a factory was established in Budapest Hungary and became one of the largest manufacturers of orthopaedic shoes, artificial limbs and callipers in pre-WWII Hungary. His book has been described as follows:

*"The author keeps the reader intrigued as to the outcomes of all the characters as they made their entrances into the story of his memoirs. He explores their frailties and their strengths, and the fight for survival that must never be forgotten! This truly wonderful chain of events is further enhanced with the author's own drawings which graphically interpret the emotional roller-coaster ride that is his story."*

In June 2007 Paul was awarded a Medal of the Order of Australia (OAM) for service to the community as a medical grade footwear practitioner and manufacturer.

Members were fortunate to have been able to purchase a signed copy of Paul's book at the Retreat. We have two copies remaining for purchase from the Polio NSW office at a cost of \$35.00 each. For those interested please phone on 9890 0946.

# Vale - Neil von Schill

by Gillian Thomas



It is with great sadness that we advise of the death of Neil von Schill, past Support Group Co-ordinator and Secretary of Polio NSW.

Neil was born in 1947 and contracted polio in 1950 in Dubbo where he was hospitalised for six months. His profession was in education and he taught for over thirty years in regional NSW, including twenty years as a Primary School Principal.

Neil joined Polio NSW (*then known as Post-Polio Network (NSW) – or, simply, the Network*) in 1992 and shortly afterwards became the Convener of the Network's Albury/Wodonga Support Group.

In 1998 Neil was forced to take medical retirement from the NSW Department of Education because of the onset of the late effects of polio. His retirement marked the start of many years of dedicated volunteer work for the Network/Polio NSW and, more recently, Polio Australia. I first met Neil in person in Canberra in 1998, at a Support Group Convenors' Workshop conducted by the Network.

At our 1999 Annual General Meeting (AGM), Neil expressed his willingness to be an advisor to the Management Committee on regional issues. He was subsequently appointed as Support Group Co-ordinator and his more remote location than previous Co-ordinators meant he brought a different perspective to the role. Neil travelled extensively around NSW (including the ACT) between 1999 and 2011, developing and nurturing Support Groups. In our Annual Reports Neil reported that it was his privilege and delight to serve his fellow polio survivors in this way, and he was unstinting in his praise for the efforts of Support Group Convenors and Regional Representatives. He was overwhelmed by the friendly response, welcoming acceptance and encouraging enthusiasm that he encountered as he maintained contact with Support Group Convenors by phone, through correspondence and personally over the next twelve years.

Neil joined the Management Committee at the 2003 AGM while maintaining his Support Group Co-ordinator role. At the following AGM Neil was also elected as Secretary and for next 7 years he more than capably managed the dual roles, and over that time became my right-hand man.

Between 2003 and 2011 Neil also arranged 5 biennial Country Conferences around NSW (Dubbo, Beresfield, Ballina, Wagga and Bomaderry) and also assisted with the organisation of Metropolitan Seminars. He organised the Polio Australasia Conference in Sydney in May 2007 and was instrumental in the agreement at that forum to form Polio Australia. He served on the Polio Australia Management Committee from its establishment in 2008 until 2011, the latter years as Treasurer. Neil was a key member of Polio Australia's lobbying delegations to Canberra where we sought funding to support Australia's forgotten polio survivors.

In 2011 Neil suffered a number of strokes, with the final one robbing him of strength on his right side (*cruelly, the side that was less affected by polio*), and severely affecting his speech. Regretfully he was no longer able to maintain his volunteer work and stood down at the 2011 AGM, creating an enormous hole at that time in our capacity to support polio survivors.

Following the strokes Neil's health deteriorated further and he was admitted to a Nursing Home. He passed away on 16 May 2014. John Tierney, Peter Garde and I represented Polio NSW at Neil's funeral in Albury the following week. Other attendees included Mary-ann Liethof, Polio Australia's National Program Manager, and Convenor Isabel Thompson (with her husband, Clarrie) from the Wagga Support Group, Convenor Margaret Bennie from the Albury/Wodonga Support Group, and Ann-Mason Furmage and Ruth Robinson from the Physical Disability Council of NSW. Apart from family members, also present were a large number of friends from Neil's teaching days and community activities. Neil was given a standing ovation at the end of the funeral service – a great send off, as befitting a man of his stature in the communities he worked in and for. Neil's wife, Gail, has asked me to thank the Polio NSW members and friends who passed their condolences on to her and her daughter, Bev – they are very appreciative of your thoughtfulness.

In conclusion, Neil did not let ego or ambition dictate his many activities – he worked in roles where he knew he could make the most impact; he didn't aspire to be a leader but he nevertheless was. His work was recognised many times over the years, including being awarded Life Membership of Polio NSW. These are a few more examples:

In 2002 the Rotary Club of Albury North presented Neil with a *Shine On Award* for his endeavours both with Polio NSW and other community organisations. The award is presented to people with disabilities who are making an outstanding contribution to their community, and who, by their actions, serve as *Shining Examples* to the community.



Neil was the 2011 recipient of the *Jack Irvine Memorial Shield*, awarded by the Disability Advocacy and Information Service, Wodonga. The Shield is awarded each year to an individual who has demonstrated qualities of leadership, self-advocacy, is a champion for community inclusion, and whose activities benefit the lives of people with a disability in the region and beyond. The award recognised Neil's work for Polio NSW, Polio Australia, the Physical Disability Council of NSW, and his active membership of the Albury Access Committee.



In presenting the Shield, Mrs Goodman, a life member of DAIS, said that Jack Irvine would have been proud of the achievements of Neil von Schill and congratulated Neil on his hard work to improve access and support services for people with disability throughout NSW and Australia.



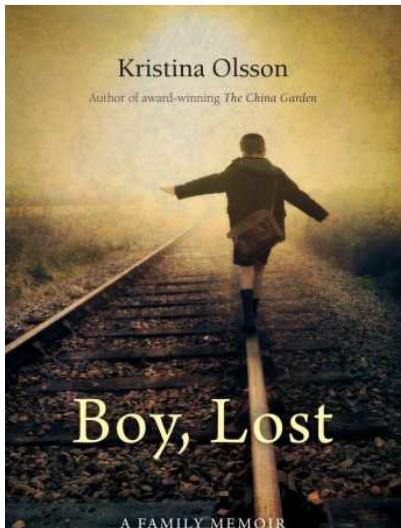
In 2013 Polio Australia presented the above plaque to Neil acknowledging his "*outstanding service over many years to Australia's post-polio community*". Neil is pictured above, holding the plaque, with his daughter, Bev (L), and wife, Gail.

I have not only lost a colleague and a dear friend, but Polio NSW, Polio Australia and Australia's polio survivors have lost a tireless worker and champion for their cause. A tribute page for Neil is online at <[tributes.smh.com.au/obituaries/smh-au/](http://tributes.smh.com.au/obituaries/smh-au/)> (select "all time" and search for "von Schill") and will be available until 20 June 2015. All entries will be passed on to Gail.

# BOOK REVIEW - "Boy, Lost" by Kristina Olsson

by Anne Buchanan  
Polio NSW Committee Publicity Officer

*This book is the story of Peter Preneas' life. It tells how he was snatched from his mother by his father as she was escaping from a brutal marriage. Peter is a former Polio NSW Management Committee member and Assistant Webmaster.*



It is somewhat difficult for me to be completely objective regarding this book as it is a 'family saga' about the family of a close friend of mine. Therefore, I have questioned a number of people who have also read the book, but who personally know nothing of the people in the story other than what they have read. Everyone I asked was of the same opinion as me in that the book is a jolly good read. In fact, one lady told me she couldn't put it down and had read it straight through in less than two days.

It is the story of Yvonne, who at a rather young age, falls in love and married. Her husband convinces her to leave the security of her family in Brisbane and move with him to Cairns where he opens a shop and where Yvonne is expected to work very hard for long hours. It is here that it becomes obvious that her husband, Michael, is not the person she thought he was. Sad and disillusioned her life becomes something of a nightmare.

After the birth of their first child, a son, Yvonne decides that a trip back to Brisbane to the comfort of her own family may help improve her life. Her secret plan being to stay in Brisbane. Sadly this proves not to be the case as just before the train leaves Cairns, Michael jumps on board, tears their son from her arms and tells her if she ever tries to get him back he will kill the baby. Believing her husband quite capable of carrying out his threat, Yvonne felt she had no choice but to relinquish her precious baby for his own safety. So they did not meet again for 32 years.

The story then tells us about the effect these events have on the lives of all concerned. Yvonne, her first born son, her relationships with her family, friends, work colleagues etc. After some time, Yvonne meets and marries another man and they have a family of their own and these children's lives are also affected by their mother's past life. It is a past they know nothing about and therefore there is so much about their mother which they cannot understand.

The family is reunited after more than 30 years and as so often happens in such cases, even this family reunification brings out rather complex and mixed emotions in all concerned. It is not all hassle free and straight forward.

Does the story have a happy ending? I guess if I tell you that Kristina Olsson, the author, is the sister of the little boy snatched from his mother's arms in Cairns, you might be able to guess the ending almost. It is the events of all those 'lost' years that make this such an interesting story.

Anne O'Halloran, Polio NSW Seminar Co-ordinator, has recently corresponded with Jillian Skinner, MP, regarding accommodation for rural and regional patients. She has passed on the reply below, hoping that it might be of benefit to some of our members.



**The Hon Melinda Pavey MLC**  
Parliamentary Secretary for Regional Health

M14/902

Ms Anne O'Halloran  
Email: [anneoh@optusnet.com.au](mailto:anneoh@optusnet.com.au)

16 APR 2014

Dear Ms O'Halloran

Thank you for your correspondence to Jillian Skinner MP, Minister for Health and Minister for Medical Research, regarding accommodation for rural and regional patients. Mrs Skinner has asked me to respond.

The NSW Government understands that issues faced by rural communities are different from those in metropolitan areas. Because of this, the Ministerial Advisory Committee for Rural Health was established to ensure the voice of rural people is heard and that their health care needs are met now and into the future.

In this regard, the NSW Government has made a significant investment, with \$3.7 billion spent on health services in 2013/14 for people living in rural areas. Since 2011 we have also made a record investment of \$1.7 billion in rural and regional health infrastructure.

Specialist health services are expanding considerably. For example, in 2002, there was just one Cancer Centre in regional NSW and in 2014 there are now seven. This means that 95% of the NSW population has access to a Cancer Centre within 100kms of their home.

However, the Government continues to provide assistance to those who require travel to a metropolitan centre. This is why the Government established the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) to provide accommodation subsidies for patients travelling 100km one-way or more. Information about the scheme can be found at: [www.health.nsw.gov.au/transport/pages/default.aspx](http://www.health.nsw.gov.au/transport/pages/default.aspx)

In relation to Blue Gum Lodge, please be advised that this is not a NSW Health facility; it is operated by an independent operator, HammondCare. Adjunct Associate Professor Vicki Taylor, Chief Executive, Northern Sydney Local Health District, advises that Blue Gum Lodge will no longer accept bookings for Royal North Shore Hospital (RNSH) patients.

Blue Gum Lodge offered 19 rooms to patients and carers, which is why RNSH has negotiated a reduced rate of stay for 19 rooms at Mary MacKillop Place, North Sydney. Mary MacKillop has 24 hour security access, onsite parking and cooking amenities in a number of rooms and is wheelchair accessible. The tariff includes breakfast at the onsite café.

In addition to this, rooms are also available at Ryde Hospital, which is wheelchair accessible and has access to a shared kitchen. Rooms at Ryde Hospital and Mary Mackillop can be arranged through the RNSH Social Work Department with accommodation subsidised by IPTAAS.

Professor Taylor has assured me that no patients have missed their treatment due to a lack of accommodation. The RNSH Social Work Department is committed to supporting all country patients with their stay, particularly those experiencing financial disadvantage. If you require any support in this regard, I encourage you to call the Social Work Department on 9462 9477.

Finally, I am also pleased to advise that new patient and carer accommodation is being planned for the RNSH for completion by 2015.

Level 31, Governor Macquarie Tower, 1 Farrer Place, Sydney NSW 2000  
Phone: (61 2) 9228 5229 Fax (61 2) 9228 5877 Email: [jillian.skinner@minister.nsw.gov.au](mailto:jillian.skinner@minister.nsw.gov.au)

In relation to Norland House, Ashfield, there have been no changes to this site and the Sydney Local Health District continues to offer all 26 rooms to accommodate rural and regional patients. Further information regarding Norland House can be obtained by contacting Ms Noeleen Franks, Patient Accommodation Officer, on 9515 9901.

For Patients accessing Royal Prince Alfred Hospital (RPAH), arrangements are also in place with several local hotels to provide patients with discounted accommodation. The distance of these hotels from RPAH ranges from a one minute walk to a 10 minute walk.

Thank you again for raising your concerns with the NSW Government.

Yours sincerely,

Melinda Pavey MLC



## MyPost Concession Card

*Reprinted from the Newsletter of IDEAS, May/June, 2014*

Australia Post has increased the cost of postage stamps to 70c each. People on a concession card are now able to apply for a 'MyPost Concession Card'.

This card will allow you to purchase up to 50 concession priced stamps each year i.e. @ 60c each. Upon application for this card, you will also receive 5 **free** concession card stamps.

To apply for a MyPost Concession Card you have to fill out an application form and take the completed form with your Government Concession Card to your local post office. You should then receive your MyPost Concession Card and the booklet with 5 free stamps within 14 days of lodging your application.

[auspost.com.au/parcels-mail/mypost-concession-account.html](http://auspost.com.au/parcels-mail/mypost-concession-account.html)



In the USA there is a growing movement to adopt a new 'disabled' symbol. The new version shows a person actively engaged with their world, rather than focusing on a passive wheelchair user. What do you think of it?

For more information visit  
[www.accessibleicon.org](http://www.accessibleicon.org)

# "Where There is a Will There's a Way" by Les Ryan

*Max Baldwin is a member of Polio NSW. He contracted polio in 1929 in Ballina NSW. He has supplied us with this article published in SKI Australia magazine, July 1963. Max states that he is now 82 and still going strong.*

Max Baldwin adjusted a ski to his boot, strapped a polio withered left leg to the right, gazed wistfully down a long stretch of snow at Kiandra, lunged a few feet and fell on his face. He grinned, got up on to the skis, and tried again. At the end of a week he had covered 40ft before crashing.

A Frenchman, who was holidaying in Australia, intently watched Baldwin each day gathering great respect for the determination of the Australian. Finally, he approached Baldwin's friend, Lionel Anet, and in the French language – he couldn't speak a word of English – he offered to show "the determined young man" how he could master skiing.

He interpreted through Anet that in Europe soldiers who had lost a leg in battle were skiing in the Switzerland Alps with the ease and agility of the average physically fit person. He showed Baldwin how he could use his self-made chromium-plated sticks he used for walking to balance and propel him. They would not quite provide the same propelling style as the small skis used in Europe but would do.

Fortunately for Baldwin his friend Anet was an expert toolmaker. During the summer months he moulded the chromium-plated drawn steel crutches into outriggers so that Baldwin could remove the rubber tips from the bottom to attach small skis of 20 inches in length. This allowed him to balance and propel himself on the snow.

The next year he started off on the gentle slopes of Kiandra and Thredbo and visited the Perisher Valley.

Today Max Baldwin is an accomplished skier, capable of taking the vertical descent from the top to the bottom of Thredbo. The steepest pinches have no terror and the slalom course no worry at all.

Baldwin has won club events at Thredbo and Perisher Valley, but as he is now a professional gymnast does not enter in any open or championship events.

Max Baldwin is one of Australia's most remarkable sportsmen. He has proved that the human being who has sufficient courage and the will to try can overcome almost any physical disability. This is Baldwin's answer to the person who is inclined to give up hope or refuses to make the attempt.

He represented Australia at the 1956 Melbourne Olympic Games as a kayak canoeist, has won the Freearm and Roman Rings individual gymnast championships of NSW, plays a good game of tennis and accounts for more people than can beat him on the squash court.

An instructor at the City of Sydney Police Citizens Boys' Club, Woolloomooloo, he holds daily classes for 40 schoolboys and an evening class for a teenage squad. Gymnasts who hope to go places in one of the most exacting sports come from all parts of Sydney for lessons.

Baldwin says, "*I am not embarrassed by a physical handicap. There was nothing I could do about it. It just happened to me. I am prepared to help people unfortunate enough to be under the same physical handicap as myself. I beg them not to pity themselves. If they come to me I will advise them what they have to do and, if they want it, give them lessons in skiing, gymnastics, canoeing, tennis or squash. They only have to pick up enough courage to 'give it a go' to discover just how easy it is. I know how these people feel because it happened to me.*"

*"At school I felt right out of the picture, as a teenager I worked in a boot factory and buried my head in books, avoided company. It was not until I was 20 years old that I attempted to play any sport."*

Today there would be a no more physically fit athlete than Max Baldwin, with the deep chest, powerful shoulders and muscular arms of a welterweight boxer.

Baldwin, born a healthy child, contracted polio at one year and nine months old. At first he was paralysed in both legs and doctors feared that he would never be able to walk.

But they persevered and aided by masseurs and the constant affection of his mother they were able to save his right leg. There was no hope of ever gaining the use of the left leg, which has remained paralysed from the hip down.

Such a disability is a tremendous handicap at school. Those years of his life were not exactly happy and he was glad when his schooldays were over.

The years after school were also trying. Max was content to go into a shell. He hated being pitied and did not seek company. Most of his spare time was spent reading books, slipping quietly into the darkness of movie theatres, hobbling home to find the comfort of his bed.

It did not help him that his brother Beres and sister Gwenda were two perfect physical specimens, expert acrobats, gymnasts and dancers. What Max didn't realise was this. His self-pity was making it tough for his brother and sister. It took them six years to convince Max that he had just as much right as anyone else to take an active interest in everyday life and sport. Finally with a lot of coaxing they got him into a gymnasium.

That was the turning point of Max Baldwin's life. He soon found out that a useless leg did not stop him from becoming expert on the parallel and horizontal bars, on the pommel horse and in freearm gymnastics. Once convinced he never gave up.

In 1950 he became the NSW Roman Rings and Freearm champion. He was a member of the YMCA A grade team that won the NSW championship in 1951. And having conquered a sport that demands the highest technique in balance, flexibility and agility, strength and callisthenic movement he knew nothing was beyond his reach.

In tennis, although he had to use one crutch, he was still able to move with a considerable amount of speed and jump quickly into half court to meet a return. He quickly overcame the difficulty of serving. Able to use only one hand he tossed the ball high into the air meeting it on the way down.

From tennis he took an active part in fencing and archery. These sports, however, took second place to the fascination of canoeing.

He took up kayak canoeing in 1952 and in 1954 he was the Australian 1,000 and 10,000 metres singles champion and the titleholder against allcomers in the 100 mile marathon. He won the 1,000 metres single kayak in 5m 10s and the 10,000 in 54m 40s, both remarkably good times 10 years ago.

The most remarkable canoeing performance was winning the 100 mile marathon. The marathon was a tough race from the Nepean Bridge to Peat's Ferry. The first 13 miles of the event to the Yarramunda Bridge were through rapids.

He cut his times in the 1,000 and 10,000 metres down considerably at the 1956 championships held on Lake Ngambi, Victoria.

He made the Australian team for the Melbourne Olympic Games and it will be remembered that the Australian canoeists put up a good showing, making every final event in the kayaks.

Squash has been Max Baldwin's latest sport. Again he was under the handicap of having only one hand to hold the small black ball and the racquet in serving. But he had learned his lesson playing tennis and it came a lot easier.

Even golf has not proved too tough a sport for Baldwin. He thinks nothing of walking over undulating ground, playing shots out of sandy bunkers over the long 18 holes.

Max Baldwin tells these stories because he is anxious to convince people with the same disability as himself that there is a place for them in sport. If they have any doubt he suggests that they come along and meet him. He will at least try to show them how.

# Ask Dr Maynard - Dr Frederick M Maynard, MD

Reprinted from *Post-Polio Health* (formerly called *Polio Network News*) with permission of Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org)). Any further reproduction must have permission from copyright holder. *Post-Polio Health*, Vol. 29, No. 3, Summer 2013.

**Question:** I am 74 years old and had polio in 1954. My recent DEXA scan (to measure bone density) showed I had osteopenia. I have also recently suffered two compression fractures in my L1 and L2 vertebra due to an automobile accident in which I drove off the road over very bumpy terrain. My longtime physician, who is familiar with my PEG (feeding) tube, wants me to have bisphosphonate infusion. What is this and is it safe?

**Dr Maynard:** I invited Mary Eulberg, MD, Denver, Colorado, family physician and polio survivor, and Daria Trojan, MD, Montreal Neurological Institute, post-polio researcher and clinician to respond with me on your question. It is one that PHI receives regularly.

**Dr Eulberg:** As you may know from past issues of *Post-Polio Health* [See Calcium, Vitamin D and Bisphosphonates, Oh My! (Vol. 27, No. 3) and More Research About Bisphosphonate Treatment in Polio Survivors (Vol. 28, No 1)], there are some controversies about bisphosphonates (oral or injection/infusion). For you who uses a PEG tube the possibility of taking the bisphosphonate pills is not an option, and thus, the side effects of irritation to your esophagus or GI tract is eliminated.

The advantage of bisphosphonates is their ability to slow down or completely stop the process of bone becoming more brittle and decreasing the risk for fractures of vertebrae, of the hip and of the wrist. The risks are that some people have developed breakdown of bone in their jaw bones (osteonecrosis) especially after extractions or other dental work that involves the jaw bone (Routine fillings, cleaning, etc., do not cause this), or in some people an increased risk of spontaneous fracture of the femur (thigh bone). Therefore, if you have been advised to have any dental work done you should do it before starting the bisphosphonate.

It is now thought that people do not need to take a bisphosphonate for a lifetime. The current thinking is that a total of five years gives the best benefit with the least amount of risk.

Your insurance will likely need some extra documentation explaining why you can't take the pills and why you need the more expensive injections or infusion. The criterion they use to approve intravenous bisphosphonates is usually a diagnosis of osteoporosis not osteopenia. But, they may decide you qualify because some experts say that a diagnosis of even a single vertebral fracture is sufficient to say a woman has osteoporosis. Osteoporosis means that the DEXA scan shows a T-score of -2.5 or greater, which means your bone is about half as dense as the bone of a normal 30-year-old. Osteopenia means that your bone is less dense than a normal young adult but not bad enough yet to qualify as osteoporosis.

**Dr Trojan:** With regard to the question about intravenous (IV) bisphosphonates in post-polio patients, we did not analyze data of patients treated with these medications in our published manuscript (Alvarez A et al. *PMR* 2010;2:1094-1103). See *Post-Polio Health*, More Research About Bisphosphonate Treatment in Polio Survivors (Vol. 28, No. 1). Outside of this group of patients, more recently, we have had a few patients treated with IV bisphosphonates and from our anecdotal experience with this very small number of patients, they seem to be well tolerated.

**Dr Maynard:** In this case, I think the dilemma is deciding if the vertebral compression fractures were a result of violent trauma, or if they were a result of osteoporosis weakening the vertebrae sufficiently that minor trauma resulted in their fracturing.

I would favour recommending treatment with vitamin D and calcium, and then a repeat of the bone scan in one year before initiating IV bisphosphonates now, because violent bouncing in a car can result in fractures regardless of bone scan scores.

## Promoting Positive Solutions by Dr. Rhoda Olkin, PhD

Reprinted from Post-Polio Health (formerly called Polio Network News) with permission of Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org)). Any further reproduction must have permission from copyright holder. Post-Polio Health, Vol. 30, No. 1, Winter 2014.

**Dr Rhoda Olkin** is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology.

**Question: Regarding the Promoting Positive Solutions column in the last issue of Post-Polio Health, Vol. 29, No. 4: I can identify with the person in the question. I also had polio as a teenager, and, like him, I am still on my own with assistance but concerned about what will happen to me if my situation worsens. I don't think the columnists understand the problem. Loss of independence is a heavier problem than is reflected by their answers; they see this problem only on the surface. It is depressing to think about transitioning from being autonomous to depending on strangers as caregivers who then become dependent on you for their livelihood. If you are a polio survivor – you have the right to be depressed!**

### Response from Rhoda Olkin, PhD:

It is good to get feedback about a previous column. I am sorry my answer seemed too superficial. I can assure you I do understand the psycho-emotional turmoil that accompanies decreases in independence, as I too age with polio and find my abilities declining and my need for assistance increasing.

Let me address the two key aspects of your comments. The first aspect is about what you call "loss of independence." Why put this in quotes? Because I want to reframe it. Having someone help you with tasks or even doing them for you is not the same thing as loss of independence. I have someone who does my laundry, changes the sheets, goes grocery shopping, vacuums, cleans, runs errands, changes light bulbs and scoops up the dead mice my cats bring me as gifts, but I still consider myself independent. That's because I ask her to do those things, and because doing or not doing these tasks myself in no way defines who I am. Independence is not an either/or – either you have independence or you don't – but a matter of degrees of independence.

As I notice changes in my functioning, I have to make adjustments. For example, I use a wheelchair more in the house than I used to, and walking the few steps from stove to sink with a pot full of boiling water and noodles became scary. So now I have a microwave container for making noodles that allows me to make them myself. Or sometimes I ask my assistant to make a big pot of noodles at the beginning of the week. But neither the change in how I do things nor the assistance in making noodles affects the essence of me: I am not defined by the noodles I make! But let's think of a harder example: At one point I had to give up using woodworking tools, hence letting go of a major hobby of mine. Of course this was a harder adjustment than the noodle-making problem. I had to find different hobbies, and truthfully, the new hobbies were not as satisfying as woodworking, so

this change required more personal readjustment than I would have wanted. Yes, I was sad, but not depressed.

Which brings me to the second point, about depression, and your assumptions: (a) that depression will accompany changes in independence, and (b) that polio survivors have a right to be depressed. I take issues with both of these points. And I say that as someone who has had more than my share of depression in my life. Depression is not a necessary or even usual response to changes in functioning. It should not be expected, it should not be thought of as typical, and it should be aggressively treated. Generally it is not the decrement in functioning *per se* that is the root of any depression, but the loss of socialization and activities that lead to depressed mood.

Longevity is most associated with continued socialization, so work on that aspect of life. And if living alone, I recommend cats – they don't need walking, there are automatic feeders and litter boxes and they cuddle!

*These articles were taken from the Spinal Cord Injuries Australia (SCIA) Accord magazine, Summer 2014. To get a copy of the publication, contact SCIA on 1800 819 775 or visit <[www.scia.org.au](http://www.scia.org.au)> for more information.*

## Hot Topic



**Q: Is there a fee for loading a wheelchair user into a wheelchair accessible cab?**

**A:** There is no separate fee for assisting a wheelchair-using passenger. In fact, the taxi meter shouldn't be running while the vehicle is being prepared for the wheelchair-using passenger. However, it is common to find that drivers start their meters and then go about the task of removing seats to free up the wheelchair space.

The driver of a booked taxi may engage the meter on arrival at the appointed time, not when they have arrived early for the booking. If the passenger comes to the taxi to find that it is not ready, he should instruct the driver to turn off the meter while it is being prepared. The same is true for a cab hailed from the street.

In NSW drivers already have a number of benefits for operating a wheelchair accessible taxi (WAT). These include an \$8.47 bonus each time they transport a person who has an M50 (wheelchair-seated journey) Taxi Transport Subsidy Scheme voucher, and a massive reduction in the licence plate fee – \$20 per week for a WAT compared to \$700 for a regular taxi.

If you experience a driver attempting to demand an extra loading fee or other wrong charges, refuse to pay them and call the booking service (02 8332 0200 in NSW) to report the incident.

## Goods & Services

Advokit is a website developed by Disability Advocacy Network Australia Limited (DANA) to support advocacy for people with disabilities in connection with the National Disability Insurance Scheme (NDIS). Whether you are a person with a disability, a family member of an independent disability advocacy agency, it aims to inform you about the rights and entitlements of people with disabilities under the NDIS and about how to achieve support from the program. Go to <[www.advokit.org.au](http://www.advokit.org.au)>.

# Golden age of Slim Dusty cast in bronze unveiled for Tamworth Country Music Festival

Joy McKean was born in 1930 and contracted polio in 1932. This article appeared in the Hunter Support Group Newsletter.

Posted Fri 24 Jan 2014, 4:54pm AEDT



**PHOTO:** Joy McKean admires the 1957 version of herself and her late husband Slim Dusty. (AAP: Lukas Coch)

Follow link: <[www.abc.net.au/news/2014-01-24/golden-age-of-slim-dusty-cast-in-bronze/5217972](http://www.abc.net.au/news/2014-01-24/golden-age-of-slim-dusty-cast-in-bronze/5217972)>

***The enduring legacy of Australian country music legend Slim Dusty is now set in bronze in Tamworth, the nation's country music capital.***

The New South Wales Premier has officially unveiled a bronze sculpture depicting the late entertainer and his widow Joy McKean, as part of this year's Tamworth Country Music Festival.

The \$180,000 artwork has been installed on Peel Street, known as the Boulevard of Dreams and the centre for buskers during the annual 10-day event.

McKean and the couple's two children, David and Anne Kirkpatrick, were also on hand along with fellow performer John Williamson, Tamworth Mayor Col Murray and the regions state MP Kevin Anderson.

McKean was overwhelmed at the public support that made the statue possible.

*"So many people have been responsible for putting it here, for building it and everything, I think that's what's marvellous to me", she said.*

*"Donations for this have come from everybody, from just the man on the street, anybody, through to government level, and that is amazing".*

Slim Dusty, real name David Kirkpatrick, adopted his stage name at the age of 11 and released scores of albums in a prolific career spanning more than 60 years.

He died from cancer in September 2003 at the age of 76.

Sculptor Tanya Bartlett – who previously provided Tamworth with a statue of another late great country star, Smoky Dawson – spent months working on the piece.

Her work captures the power couple in their prime, around the time of the 1957 release of arguably Slim Dusty's biggest hit, "A Pub With No Beer".

Then Premier Barry O'Farrell told those gathered for the unveiling that the statue recognises the enormous contribution Slim Dusty and McKean made to Australia's music heritage.

*"Having a statue immortalising Australia's King of Country will no doubt become another drawcard for visitors to the area", Mr O'Farrell said.*

*"A monument to a decent couple who ... continue to contribute through their extended family, a monument to the country music that's helped shape generations of us who've lived in this country.*

*"But above all a monument to the stories they tell about ordinary Australians that have helped make this the best country in the world".*

---

## Polio Health and Wellness Retreat: 8-11 May 2014

**by Nola Buck, Co-editor**

On Thursday, 8<sup>th</sup> May, I set out for the St. Joseph's Centre for Reflective Living. This Centre is not far from where I live and each time I visit it, I think of it as an oasis in the middle of suburbia. Its smooth expansive lawns, interspersed with trees, its beautiful gardens brightened by roses and tubs of Spanish Jasmine, could not help but lift the spirit, sharpen the mind and focus the body away from its deficiencies. It is an ideal venue for a Retreat concentrating on the Body, Mind and Spirit, especially the Spirit, as it is a former Convent of the Sisters of St. Joseph and reminders of their founder, St Mary of the Cross MacKillop (Australia's first saint) are everywhere.

Sixty-one people, the majority of whom had contracted polio, were gathered to hear many speakers and engage in various activities. Some were Retreat Junkies, a title they have given themselves, as they have attended several Retreats, others were at their second retreat and others their first. Each person absorbed the Retreat in a different way, and this article will be how I absorbed the Retreat with information gleaned from others during the final session.

On Thursday afternoon, after getting our bearings (the building has many floors, passages, small rooms and comfortable bedrooms), we gathered for a meal. Later in the evening we were welcomed by Dr John Tierney, President of Polio Australia, Gillian Thomas, Vice President of Polio Australia and President of Polio NSW and Mary-Ann Liethof, National Program Manager, Polio Australia. Following the welcome each attendee introduced her/himself and spoke about what she/he expected from the Retreat. We then heard from Paul Galy, whom many of you may know as the maker of their shoes. Paul spoke about his book, "The 4<sup>th</sup> of May". This book was reviewed in Network News Issue 83, and it is a story of a family's survival during a dark age of our history. Paul stated he felt so relieved after the events in his family's life had poured from him in his writing but he felt strangely exposed in revealing so much of the family's (and his) experiences.

At the Retreat, were John and Faye Powell from Mittagong. Faye had written a book, "*Matthew Pearce and The Howlong Connection*". John is a descendant of Matthew Pearce a pioneer of The Hills district and who once owned the land on which St. Joseph's had been built. Matthew built Bella Vista a beautiful home maintained by Baulkham Hills Shire Council and also an oasis in a mixed residential and industrial area.

On Friday the hard work began, learning about the Healthy Body. As in each section of the Retreat, there was one plenary session at the beginning, "*The Polio Body*", presented by Dr Stephen de Graaff, Senior Rehabilitation Physician, Epworth Healthcare, Victoria. Dr de Graaff spoke on the initial polio infection and what occurred in the body, the advent of post-

polio syndrome and the late effects of polio and the difference and the management of both. His talk will be on the Polio Australia Website, along with other Retreat presentations.

Following the Plenary session were concurrent sessions all based on the Polio Body. This was the format for the rest of the Retreat. Interspersed between sessions, were massage sessions, displays from the Independent Living Centre of NSW of assistive technology, AutoMobility, Barefoot Freedom Footwear and, of course, meals. The day concluded with a performance from the Circular Keys Chorus, proponents of the art-form of barbershop harmony.

Saturday, The Healthy Mind, commenced with a plenary session entitled, "*Healthy Brain Ageing*", by Dr Loren Mowszowski, from the Brain and Mind Research Institute, the University of Sydney. This was one of the best sessions, probably because most of us could relate to it. She gave examples of incidents, losing our car keys and forgetting that word. She assured us that this is quite normal, because as the body ages, so does the brain, but it could also indicate something else is going on and to seek help if one is concerned about it. She gave us little exercises to illustrate her statements.

Again, there were sessions such as Seated Yoga, Early Polio Memories, Telling Your Story and a Family History Taster and many more with massages and consultations, interspersed between them. There was also a session for partners of a person who has had polio.

The day concluded with a visit from the Comedian, Tommy Dean. This was a very enjoyable segment of the Retreat, made more so because of a discussion as to whether Tommy had contracted Polio or Guillain Barre Syndrome as a child. After much discussion and advice to Tommy, we still don't know what he contracted, but he is certainly one of us, he has a disability.

Sunday was the final day of the Retreat. The final day is always different, people are often sad to be leaving newly formed friends, they are hurrying to pack and get their bags away and they are distracted by the impending return to normality. "*The Healthy Spirit*" is not an easy topic, but it was well illustrated by Sr Annie Bond, Centre Director, St Joseph's, Baulkham Hills in her plenary session.

Sr Annie spoke of how the spirit is intangible but an integral part of the body. She spoke of how beauty takes a person beyond mundane things – that is spirit. She spoke of the joy when she returns to St. Joseph's, the beauty of the place, and the spirits which have been here – the spirits of the pioneers and Religious.

The day concluded with a closing plenary where everyone spoke on what they had gained from the Retreat. To the first-timers, the knowledge they had gleaned from the various speakers and how that knowledge could assist them in managing their new symptoms was invaluable. To the Retreat Junkies and others there was always something new to learn, but also the making of new friends and renewing friendships was also of high importance.

We left on a high and looking forward to the next Retreat at Torquay, Victoria in 2015.



A note from the editor: Remember to visit the Polio NSW and Polio Australia websites for lots of useful information for members and health professionals and to view past seminar presentations.

Polio NSW: <[www.polionsw.org.au](http://www.polionsw.org.au)>      Polio Australia: <[www.polioaustralia.org.au](http://www.polioaustralia.org.au)>

# Polio Post



*I think we are all aware of the great work that Gary and Barbara Fuller do to support our members by promoting Polio NSW Support Groups. Gary recently forwarded to me an email which follows; Gary stated: "When you get a letter like this it makes the job worthwhile. Neville comes from Cherry Tree Hill, near Inverell and has been a farmer all his life.".*

*Neville Bryant is a 73 year old farmer who has "been through the pain barrier many times over the years since he contracted polio, just doing the things that he wanted to do in life – being a food producer, a farmer". Neville is a member of Inverell Rotary and has been a guest speaker about his polio and his recent experience. Here is his email followed by stories written by Inverell Rotary Club members about Neville.*

Hello to you both

It was such a nice surprise to receive your phone call of welcome to Polio NSW Inc, Gary.

I'm very much a bush boy and I guess that's partly the reason why I had never heard of Polio NSW until I got into real trouble last year. I spent two months in hospitals (Warialda-- Tamworth-- John Hunter-- Tamworth again) finally being discharged with papers marked "Diagnosis inconclusive". To shorten a long story my dear wife (a former RN) found you via the internet and we made contact. On receipt of the booklet on PPS all mystery vanished as it detailed my symptoms so accurately. In all the time in hospitals we could not find a single doctor prepared to even discuss the possibility that my problem may have in fact been the late effects of POLIO. I had been aware of this condition for many years but mistakenly believed it came back in about 30 or 40 years, I had 62 yrs. behind me.

Barbara, as a child you may have heard the name "Sister Kenny". I certainly did, as she had developed the best known methods of treating Polio children. Interestingly Sister Kenny was born in Warialda, about 50kms from us, but eventually went to USA and spent most of her life there. You can read about her if you google Sister Kenny. Also you can read a little of my polio related activities if you google Inverell Rotary and scroll down.

Thank you both for what you are doing and all the best with your efforts to have PPS introduced to medical students at Sydney University. The doctors and nurses that looked after me last year were truly wonderful and I would not have a derogatory word spoken about them, PPS was beyond their horizon.

Thank you again, and best wishes to you both.

Neville Bryant

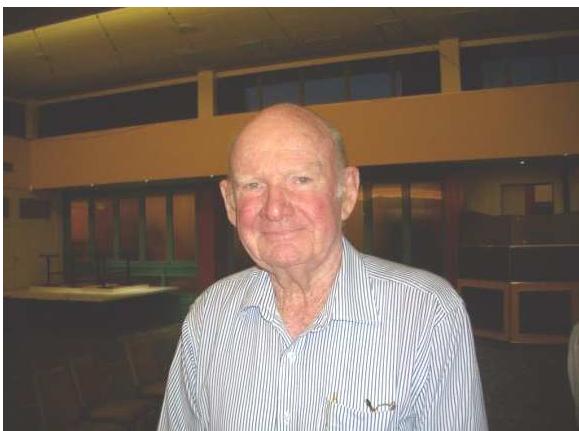
{The journey I was on during those months I would wish upon no one. I was having blood tests (*one sample even being sent to vet. lab. in Victoria looking for Ticklia disease, carried by ticks*) taken repeatedly, X-rays, CT scans, all repeated several times searching for that elusive cancer, tumour, virus or whatever. I even had a camera down my throat, a bone marrow biopsy and a check on every organ in my body all with negative results. During all of this time I can only describe my condition as semi-conscious. I stand 186cm tall, do not carry excess weight but dropped to 70kgs in weight, looked like a POW and was anorexic. Words spoken directly to me would arouse me but mostly I was somewhere else. Words of significance to me would also arouse me. On one occasion for example a doctor said "*whatever it is that is wrong with you, you may have to defeat yourself as we can't find what it is*". Dorelle was able to tell me it was a doctor as I did not know who had said it. A lot of the anxiety, stress and worry for me and my family could have been avoided if PPS had been considered.}

**Editor's Comment:** *I think it is helpful to other polio survivors to see what can happen to them if we are NOT equipped with the necessary knowledge and information to help us take charge of our own health issues.*

# Stories taken from the Inverell Rotary Website

by Sue Moran

Feb 20, 2014



**Neville contracted Polio as a young boy. He has spoken to both the Sunrise group and the evening group about his experiences when he developed the disease and then his terrible experiences last year with a mystery illness which he now believes was Post-Polio Syndrome.**

The Rotary Foundations main focus is the eradication of Polio from the world. No-one would agree with this more than Neville who has experienced the long-term effects of this dreaded disease. Neville was fortunate that his treatment after contracting the disease included the ground-breaking work of Sister Elizabeth Kenny born in Warialda. This treatment stopped the paralysis of the muscles that is often a long-term effect of Polio. However, he has suffered from a weakening of his leg muscles and this has prevented him from participating in many of the sports that have so interested him all his life.

Last year Neville contracted a terrible illness that caused him to spend many months in hospital. Doctors did test after test but could not make any satisfactory diagnosis except that it appeared to be some sort of auto-immune disease. Neville has done his own research and now feels sure that his illness was a result of what has been named Post-Polio Syndrome. Many doctors who have had no experience with Polio and its long-term effects do not recognise the symptoms. Even though Polio has effectively been eradicated from Australia because of a very effective vaccination programme there are still very many people in Australia around Neville's age and older who are Polio survivors and could be suffering as Neville has suffered.

One thing Neville is sure about is that the sooner Polio is eradicated off the face of the earth the better and that is another reason to support Polio Plus.

**Sunrise group runs a very successful Polio Plus campaign**

**Sue Moran Dec 11, 2013**



Decked out in their bright red End Polio Now t-shirts, members of the Sunrise group took to the streets of Inverell selling badges and cupcakes. They were very happy to raise around \$670 for the fight against polio. They also gained publicity for the campaign through radio and newspaper. Neville Bryant, a member of Inverell Rotary and a polio survivor was a very interesting speaker when he spoke to the group about polio and his recent illness which was of post-polio syndrome.



# Advance Care Planning

*Reprinted from the Newsletter of IDEAS, March/April, 2014*

With all the talk around making decisions and planning for your future, we thought we would take a closer look at planning in regards to your health.

Making decisions about your future health care is called advance care planning. It's estimated that up to 50% of Australians will not be able to make or express their own decisions when they are near the end of their life.

So advanced care planning is a good way to make sure that your wishes around your health care treatment are known, documented and respected. It can help those closest to you to make health care decisions on your behalf if you became too unwell in the future to make decisions for yourself.

On the Advance Care Planning Website there are a series of steps you can go through to assist you in the process and include:

- Thinking about your past health experiences
- Thinking about your current health and your future medical care
- Planning your care (taking into account your individual situation)
- Choosing someone to speak for you (your substitute decision maker)
- Writing down your wishes
- Informing others of your decisions
- Regularly reviewing your Plan

There are also a number of videos you can watch to hear from people who have put a plan into place as well as information from health care professionals.

For Aboriginal and Torres Strait Islander people there is also a booklet called Taking Control of YOUR Health Journey available to download.

There are a number of fact sheets featured on the site which have been translated into a range of community languages. The website also has links to some great resources in each state of Australia as well as a number of publications for further reading on advance care planning. To find out more information you can visit:

Advance Care Planning Australia <[www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)> ph: 03 9496 5660.

Of course if you don't have access to a computer and would like IDEAS to send you some of this information, then please give one of our Information Officers a call on 1800 029 904.



# Companion Card NSW - New Website

*Reprinted from the Newsletter of IDEAS, March/April, 2014*

Companion Card NSW has recently launched a new website. It features a search feature to find venues that accept the Companion Card as well as stories and how to apply for the program.

The Companion Card is a not-for-profit program, funded by the NSW Government and managed by National Disability Services. The Companion Card is also available in other States and Territories of Australia.

The card itself is the size of a credit card, with the name and a photo of the holder – who is the person with disability. When the holder buys a ticket for themselves at selected venues and facilities around NSW, their companion will get free entry.

A companion can be a partner, family member, friend, volunteer or paid carer.

## **Applying for a Companion Card**

When applying for a Companion Card you will be assessed against the eligibility criteria. To be eligible you must:

- Be an Australian citizen or resident, and live in NSW;
- Have a significant and permanent disability;
- Need significant support with your mobility, communication, self-care and planning to get to most venues and take part in most activities in the community;
- Not be able to get that support by using aids or other technologies;
- Have a lifelong need for this type of support.

You must fill out a hard-copy (paper) application form and post it to the NSW Companion Card team at Companion Card.

## **You can get an application form by:**

Phoning the Companion Card information line on Freecall 1800 893 044, emailing [companioncard@nds.org.au](mailto:companioncard@nds.org.au) or downloading and printing a form from the Companion Card website <[www.nswcompanioncard.org.au](http://www.nswcompanioncard.org.au)>.

You can also contact one of our Information Officers here at IDEAS and we will be happy to send one to you if you don't have access to a computer. Call us on 1800 029 904 to get in touch.



# Australian Disability Parking Scheme

*Reprinted from the Newsletter of IDEAS, March/April, 2014*

There have been some changes made recently to the Australian Disability Parking Scheme around eligibility and contact details for applying for the permit, so we have gathered the details here for you.

**NSW** – Roads and Maritime Services (RMS) – 132 213 (General Customer Service)

**Of Note:** RMS is changing the way they print and issue photocards moving to a centralised card printing service. This means at certain locations, when you apply for or renew a mobility parking card, you won't receive it on the spot – your card will be posted to you at no extra cost within five business days.

**QLD** – Department of Transport and Main Roads – 132 380 (Registration and Licensing)

**VIC** – VIC Roads – Contact your municipal councils

**ACT** – Road Transport Authority – 132 281 (Canberra Connect)

**TAS** – Transport Access Scheme – 1300 851 225

**NT** – Local Government Association – Contact NT Local Councils to apply

**SA** – Government of South Australia – 131 084 – Service SA Customer Service Centre

**WA** – ACROD Parking Program – 08 9242 5544

You can also visit the Australian Disability Parking Scheme website which has all the links for each state and territory. It gives you information on how to apply and application forms to download. Visit <[www.disabilityparking.gov.au](http://www.disabilityparking.gov.au)>.

Once you receive your disability parking permit you need to check the local rules for parking and obey all other road and parking conditions.

If you would like any further information on parking permits please give one of our Information Officers at IDEAS a call on 1800 029 904.

---

## Consumers Health Forum of Australia

*The Consumers Health Forum of Australia (CHF) is the peak organisation providing leadership in representing the interests of Australian healthcare consumers. CHF work to achieve safe, good quality, timely healthcare for all Australians, supported by the best health information and systems the country can afford. CHF member organisations reach Australian health consumers across a wide range of health interests and health system experiences. CHF media releases are available online at <[www.chf.org.au](http://www.chf.org.au)>. PO Box 3099, Manuka ACT 2603. Telephone 02 6273 5444, email: <[info@chf.org.au](mailto:info@chf.org.au)>. The following articles are reprinted from the Newsletter of the Consumers Health Forum of Australia, Vol 8, Issue 1, Feb 2014.*

## **Prescribing Pathway Welcomed by Consumers**

CHF has welcomed the move of Health Ministers to approve the Health Professionals Prescribing Pathway (HPPP), which will deliver a national approach to safe, competent and consistent prescribing of medicines by health professionals other than doctors.

CHF has been working with Health Workforce Australia (HWA) since 2012 to support the development of the HPPP. CHF facilitated a consumer forum and workshop to HPPP in 2012. In 2013, and following additional consumer engagements and consultation, CHF was one of many stakeholders to provide a formal submission to HWA on HPPP.

CMF's submission highlighted the need to be clear on the role the consumer would play in communicating with their provider about medications, and several of these recommendations are reflected in the final report.

CHF congratulates HWA on this important initiative. This will see a nationally consistent approved pathway that supports prescribing by health practitioners other than doctors. This will improve access to prescriptions for consumers in a way that maintains safety and quality. CHF will continue to support the implementation of HPPP.

The pathway and the accompanying report can be viewed at the HWA website <[www.hwa.gov.au](http://www.hwa.gov.au)>.

## **Changes Proposed to the TGA**

Changes to the Therapeutic Goods Administration (TGA) have been proposed as part of the *Therapeutic Goods Amendment Bill 2013*, which amends the *Therapeutic Goods Act 1989*. The Bill was introduced prior to the 2013 Federal Election and received bipartisan support.

The new Government has made some changes but will go ahead with legislative change in this area. The amended Bill aims to ensure consistent regulatory treatment of different types of therapeutic good and to streamline the operation of a number of provisions under the act. This will include giving the Minister the power to exclude goods from the scope of the regulatory scheme under the TGA – such as magnetic underlays and power bands. These products may then be regulated under consumer protection laws through the Australian Competition and Consumer Commission.

The Bill also gives powers to the Secretary of the Department of Health to remove certain items from the Australian Register of Therapeutic Goods (ARTG) if they are not therapeutic goods. There is currently no mechanism to remove these products from the ARTG.

The Bill also makes the provision of false or misleading information a new offence.

CHF is reviewing the Bill and investigating the impact it might have on medical devices and other therapeutic goods. CHF will provide a submission to the Bill's exposure draft, which will draw on our previous calls for reform on the TGA.

## **AllTrials Campaign Gains Momentum**

CHF has welcomed the introduction of laws to the European Parliament that would ensure that researchers running clinical trials must register them and publish summary results. This builds on the work of the AllTrials campaign, which CHF supports.

Representatives from every European Union member state have agreed with the draft Clinical Trials Regulation, and the agreement will soon be ratified by the European Parliament and the Council of Ministers.

CHF congratulates all involved with the campaign and looks forward to further progress on the AllTrials campaign internationally.

More information about the campaign can be found at <[www.alltrials.net](http://www.alltrials.net)>.



# 2014 Polio NSW Seminar Program

<b>Wednesday 23 July</b>	Northcott Building Fennell Street Parramatta	<b>Ms Jenny Ly – Arthritis and Osteoporosis NSW</b> <b>Mr Robert McLeod – Sydney Cochlear Implant Centre</b> <b>Emeritus Prof Barry Baker – Prof of Anaesthetics, Sydney University</b> – Full Seminar details on page 2
<b>Saturday 18 October</b>	Gungahlin Lakes Cnr Gundaroo and Gungahlin Drives Nicholls ACT	<b>Country Seminar – Canberra</b> Speakers and Topics TBA Further details in the next <i>Network News</i>
<b>Saturday 29 November</b>	Burwood RSL 96 Shaftesbury Road Burwood	<b>Annual General Meeting</b> <b>25<sup>th</sup> Anniversary Lunch</b> <b>End-of-Year Seminar</b>

## Management Committee – Executive Members Contact Details

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

## PPN Office and Other Contact Details

<b>Office staff:</b> George, Fatma. John	<b>Volunteers:</b> Nola Buck	office@polionsw.org.au	02 9890 0946 02 9890 0953
Anne O'Halloran	Seminar Co-ordinator	seminar@polionsw.org.au	02 8084 8855
Alan Cameron	Website Webmaster	webmaster@polionsw.org.au	0407 404 641
Mary Westbrook	Q's about polio & PPS	askmary@polionsw.org.au	02 9890 0946
Nola Buck/Susan Ellis	Co-editors Network News	editor@polionsw.org.au	02 9890 0946

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

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 polio survivors on the Register and this number increases daily. To make the Register truly reflective of the unmet need for polio services throughout Australia, all State polio networks are urging every Australian polio survivor to join the Register which is available on Polio Australia's website at <[www.polioaustralia.org.au](http://www.polioaustralia.org.au)>. The Australian Polio Register form can either be completed online or downloaded (by you, or a friend with internet access) for completion and subsequent return to Polio Australia.