

POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

Welcome to the first *Network News* for 2014. This issue is running later than we had planned but circumstances beyond our control have unfortunately delayed its finalisation.

This is a very big year for Polio NSW, and for our members, with a number of events and activities scheduled. If at all possible, we hope that you will take advantage of the opportunity to get involved in at least some of these.

From 8 to 11 May, Polio NSW is hosting Polio Australia's annual "Polio Health and Wellness Retreat", in Baulkham Hills. As Polio Australia can only bring the Retreat to each State once every four years you don't want to miss attending the NSW Retreat this year. I really encourage you to join us. The Retreat is a residential, fully-inclusive event and very reasonably priced: the registration fee which includes 3 nights' accommodation, all meals and most activities is \$350 per person double / \$400 single. Brief details of the Retreat Program are provided on pages 2 and 3, and the related documents, including the Registration Form, can be downloaded from the Polio NSW website. If you do not have internet access, just ring the Office to have the documents posted out to you. For any questions about the Retreat, please contact either the Polio Australia Office (phone: 03 9016 7678 or email: office@polioaustralia.org.au) or the Polio NSW Office (phone: 02 9890 0946 or email: office@polionsw.org.au). We look forward to seeing you there.

From 1 to 4 June, Rotarians from around the world are coming to Sydney for the 105th Rotary International Convention. Polio Australia is thrilled to have been allocated a stall in the "House of Friendship" (re-named "The Billabong" for Sydney 2014). The Billabong will be where the world of Rotary International comes together and will give Polio Australia a unique opportunity to showcase its work and promote to many thousands of Rotarians the need for support for polio survivors. Polio NSW is partnering with Polio Australia in this important awareness-raising venture, and is seeking your help to ensure we can adequately staff the stall across the 4 days, and thereby effectively get our message out. Please contact George in the Office if you are able to assist.

The mid-year Seminar will be held on Wednesday, 23 July, at the Northcott Building, Parramatta. Preliminary speaker and presentation details are given on page 22 and final information and a Registration Form will be included in the next *Network News*.

Our first Country Seminar was held in Canberra in 1998, and this October we will return to the ACT for an encore, ably supported by our ACT Support Group led by Brian Wilson. If there is sufficient interest from Support Group Convenors around NSW we are also hoping to hold a Convenors' Workshop in conjunction with the Seminar. Details of the date, venue and program will be provided in upcoming issues of *Network News*.

Our final event for the year, the Annual General Meeting and Seminar, will be held at the Burwood RSL Club on Saturday, 29 November. This year at the AGM we are also celebrating our 25th Anniversary which is quite a milestone. More details will be provided in due course.

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Polio Health and Wellness Retreat - 8-11 May 2014

Body / Mind / Spirit

St Joseph's Centre for Reflective Living, Baulkham Hills, NSW

Note: this Retreat is a fully residential experience and there is no 'day only' option



Polio Australia ran its first Health and Wellness Retreat in Baulkham Hills, New South Wales, in 2010, with a second in Mt Eliza, Victoria, in 2011, a third on the Sunshine Coast, Queensland, in 2012, and the fourth in Glenelg, South Australia. These were all based on a Polio Retreat held by Post-Polio Health International in Warm Springs, Georgia, USA, in 2009, which was attended by five Australians – four being polio survivors.

The Warm Springs Retreat focused on 'Body, Mind, Spirit' and this theme has also proven to be a very effective framework for our Australian Retreats, as it takes a holistic approach towards Chronic Condition Self Management for polio survivors, their families and carers.

Polio Australia's Health and Wellness Retreat 'open circle' Question and Answer format is a valuable self-management tool – especially the sharing of experience by the participants. The forums fully engage all participants in free-flowing discussion and information exchange, resulting in a clearer understanding and better retention of the management strategies being presented.

The knowledge gained during these Retreats has not only assisted participants to better manage their own condition, but is also being shared with their health professionals, thereby facilitating improved care for other patients presenting with the Late Effects of Polio.

This fifth Retreat is back where it all started, at the peaceful sanctuary that is St Joseph's Centre for Reflective Living. The Retreat promises to build on previous sessions and participant feedback to present a range of self-management techniques which will enable participants to achieve general wellbeing, as well as providing options for people to remain as mobile and independent as possible.

REGISTER NOW FOR THE RETREAT !

Visit the Polio NSW website at <www.polionsw.org.au/retreat-2014> to download the Retreat Program and Presenters' details, and the Registration Form. To ensure that the Retreat environment is conducive to friendly networking, numbers have been restricted to 70 people. Preference will be given to New South Wales residents and those interstate people who have not attended previous Retreats. This does not preclude previous participants from registering and paying. Bookings are only confirmed when payment is received and places allocated.

The next page gives an overview of each day's plenary and workshop sessions. There will also be displays, consultations and therapy treatments, and entertainment.

Thursday – 8 May 2014

Registration and Welcome Dinner with Guest Speaker Paul Galy talking about his book
“*The 4th of May: The Memories of Paul Galy OAM*”

Friday – 9 May 2014

Plenary – The Polio Body with Dr Stephen de Graaff

10:30 am to 12:00 pm

Concurrent Sessions

- ❖ Post-Polio Exercise Options
- ❖ Functional Footwear
- ❖ A Breath of Fresh Air: how to work with your respiratory system to maximise speech and swallowing functions
- ❖ Pain and Fatigue Management

2:00 pm to 3:30 pm

Concurrent Sessions

- ❖ Osteopathic in Self Care
- ❖ Swollen Polio Legs
- ❖ Too Tired to Breathe?
- ❖ Managing Arthritis and Osteoporosis
- ❖ Partnering Polio

4:00 pm to 5:30 pm

Concurrent Sessions

- ❖ Mindfulness: Resilience, Performance and Positive Mental States
- ❖ Optimal Nutrition
- ❖ Avoiding Falls
- ❖ Taking Charge of Your Own Health

Saturday – 10 May 2014

Plenary – Healthy Brain Ageing with Dr Loren Mowszowski

10:30 am to 12:00 pm

Concurrent Sessions

- ❖ Seated Yoga
- ❖ Early Polio Memories
- ❖ Singing for Fun!
- ❖ Mind Matters

2:00 pm to 3:30 pm

Concurrent Sessions

- ❖ Telling Your Story
- ❖ A Family History Taster: Catching The Bug!
- ❖ Cryptic Crosswords
- ❖ Travelling Options for People Ageing with a Physical Disability
- ❖ Partnering Polio

4:00 pm to 5:30 pm

Concurrent Sessions

- ❖ Card Making
- ❖ Making the Most of Our New Reality
- ❖ Laughter: The Best Medicine
- ❖ Bonsai Magic

Sunday – 11 May 2014

Plenary – The Healthy Spirit with Sister Annie Bond

10:30 am to 12:00 pm

Concurrent Sessions

- ❖ Awakenings the Creative Spirit Within
- ❖ Philosophically Speaking
- ❖ Meditation

Transport Assistance

Is it difficult for you to attend Seminars, Support Group meetings, or special events such as the *Polio Health and Wellness Retreat*?

The Federal Government's Volunteer Grants scheme included the possibility for funding of "A contribution to the reimbursement of fuel costs ... the reimbursement of fuel/petrol costs for an organisation's volunteers who use their own cars to transport others to activities, deliver food and assist people in need."

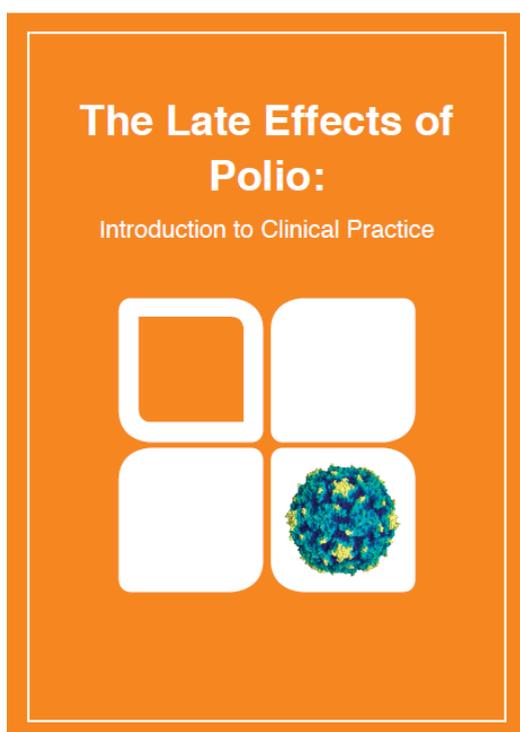
Polio NSW obtained funding under this program with the statement in our submission being:

Fuel vouchers will enable more volunteers to be recruited to assist polio survivors who are not able to drive or use public transport to access support groups, seminars and other activities. Such activities would reduce the chance of social exclusion.

Note: A volunteer in the terms of the grant does not include staff, members or participants of the organisation. This means that we aren't able to use the grant to pay one member to drive another member.

SO: If you can arrange for a neighbour, someone from your church, club, social group etc to drive you to Polio NSW and Polio Australia activities we will give them a \$20 fuel voucher to assist them to convey you to the activity. If you are in a country area and do not live in town contact the Office to negotiate a more appropriate reimbursement.

You will need to advise the Office or the organisers of the activity so we can record the date, the location, and the names of yourself and your driver in order for us to acquit the grant to the Department. The address of the driver will be needed if a voucher is to be mailed.



This resource module for health professionals was commissioned by Polio Australia and completed in October 2012. "The Late Effects of Polio: Introduction to Clinical Practice" was professionally written and reviewed by a team of volunteer medical professionals, with content drawn from a large number of pre-existing resources based on best-practice principles.

The module is a great resource to pass on to your doctor. The content provides an overview of the broad range of symptoms associated with the Late Effects of Polio and Post-Polio Syndrome, and will assist your health team in managing your problems.

Although originally designed as an online resource only, in order to make the module more accessible Polio NSW now has a quantity of printed copies available for sale at \$15 each (post free within Australia). Contact the Office to buy a copy.

Post-Polio Support Groups are Valuable to You

by Gary Fuller, Support Group Co-ordinator

How often has your GP diagnosed your problem by saying “*you are over 70 years old and should expect to feel this way*”. He or she has probably never studied polio, as it is considered a ‘dead’ disease, and they may either have never heard about polio’s late effects or know little about them.

This does not help the 400,000 polio survivors in Australia many of whom often “doctor shop” at great expense both to themselves and the health system, simply trying to find someone who is familiar with their condition and understands their difficulties. Fortunately, there are a number of medical professionals in Australia who do know about the new problems experienced by the polio community, **but where do you find them?** This is how:

- Become a member of **Polio NSW**
- Read **Network News** and **Polio Oz News**
- Attend **Polio Australia’s “Polio Health and Wellness Retreat”**
- Attend the **Polio NSW mid-Year Seminar**
- Attend the **Polio NSW end-of-year AGM Seminar**

But best of all:

Join a **Polio Support Group** and talk to other Group Members who may have experienced similar problems to those you have and have been successfully treated. Find out where to go to consult one of these very special Medical Professionals. **GOOD LUCK.**

A membership benefit of Polio NSW is that you can join and participate in your local Polio Support Group. So why not telephone the Convenor of the Group that is nearest to you and join? **These are the Groups that are running strongly:**

Polio Support Group ACT

CONVENOR: Brian Wilson 02 6255 0875

Polio Support Group ALBURY/WODONGA

CONVENOR: Margaret Bennie 02 6021 5568

Polio Support Group CENTRAL COAST

CONVENOR: Wayne Woolley 02 4342 6145

Polio Support Group HILLS DISTRICT

CONVENOR: Moya Adams 02 9144 3830

Polio Support Group HUNTER

CONVENOR: Wendy Chaff 02 4957 5254

Polio Support Group INNER WEST

CONVENOR: Claire Dawson 02 9713 6565

Polio Support Group NEPEAN

CONVENOR: Madeline Coelho 02 4751 1272

Polio Support Group NORTHERN BEACHES

CONVENOR: Pat Featherstone 02 9970 7790

Polio Support Group NORTHERN RIVERS

CONVENOR: Rosalie Kennedy 02 6687 9640 / 0412 827 926

Polio Support Group PORT MACQUARIE

CONVENOR: Gail Hassall 02 6581 4759

Polio Support Group SHOALHAVEN

CONVENOR: Dorothy Schunmann 0407 521 979

Polio Support Group SUTHERLAND

CONVENOR: Ruth Hatton 02 9525 3987

Polio Support Group WAGGA WAGGA

CONVENOR: Isabel Thompson 02 6926 2459

Polio Support Group WOLLONGONG

CONVENOR: Dorothy Robinson 02 4229 6221

These are also a number of Groups that have been very active over the years but at the moment they desperately need new members and it would be a plus for you as well as the Group if you were to telephone the Convenor of one of these Groups near you and join.

These are the Groups that need your support:**Polio Support Group BANKSTOWN**

CONVENOR: Pam Solomon 02 9773 7679

Polio Support Group CANTERBURY/MARRICKVILLE

CONVENOR: Maura Outterside 02 9718 5803

Polio Support Group COFFS COAST

CONVENOR: Shirley Barnet. 02 6651 9098

Polio Support Group CONDOBOLIN

CONVENOR: Bill Worthington 02 6895 2870

Polio Support Group DUBBOCONVENOR: *We need a volunteer to convene this Group***Polio Support Group GRIFFITH**

CONVENOR: Dawn Beaumont-Stevens 02 6963 0880

Polio Support Group METROPOLITAN EVENING

CONVENOR: Maura Outterside 02 9718 5803

Polio Support Group NYNGAN

CONVENOR: Ruth Williamson 02 6832 1220

These Convenors are hardworking, always helpful and generous of their time, Convenors are not the only Polio NSW members who are always there to be of service, there are also the **POLIO REGIONAL REPRESENTATIVES** who are there to help and assist members on where to find a Polio Support Group or assist with any other Polio NSW matter in your area. **The Polio Regional Representatives are:**

| | | | |
|--------|-----------------|--------------------|--------------|
| AREA — | ARMIDALE | Doug Crocker | 02 6772 8335 |
| AREA — | BLANEY/COWRA | Heather Drady | 02 6367 5095 |
| AREA — | ORANGE/BATHURST | Michael Hutchinson | 02 6362 8867 |
| AREA — | URALLA | Daphne Field | 02 6778 4455 |
| AREA — | MUDGEES | Ella Gaffney | 02 6372 1217 |

I am sure they would love to hear from you.

Remember the “Polio Health and Wellness Retreat” is being held at St Joseph’s Centre for Reflective Living from Thursday 8th to Sunday 11th May 2014 – you owe it to yourself to go.

Gary Fuller, Support Group Co-ordinator

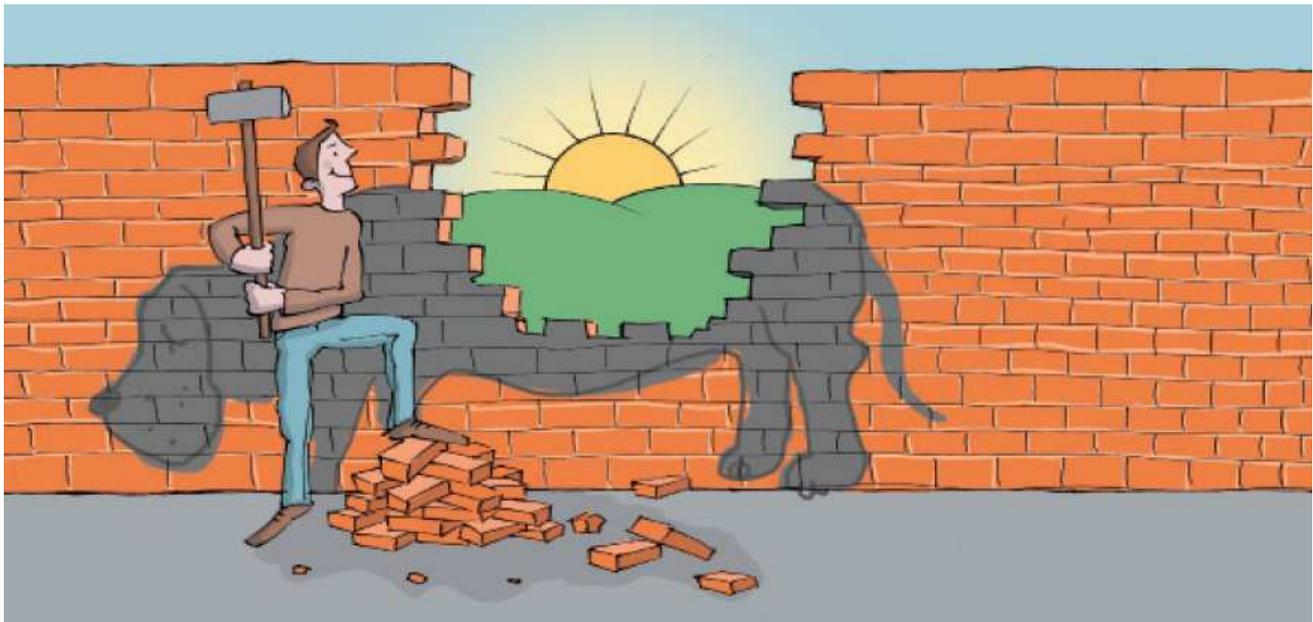
Phone: 02 9523 2428 Email: garyfuller@bigpond.com

Seminar Report - AGM 30 November 2013

by Susan Ellis, 2013 Seminar Co-ordinator

Anne Reddacliff is a volunteer Community Presenter with the Black Dog Institute. She works as a librarian, and is currently completing a PhD in happiness studies. Anne was diagnosed with Bipolar 1 Disorder at 20 years of age. Anne is passionate about mental health awareness and this has motivated her to share her story to help others. Anne's presentation covered features of depression and bipolar disease, getting help, increasing well-being and resilience.

Breaking Down Depression and Building Resilience



About the Black Dog Institute:

- The name “Black Dog Institute” comes from the metaphor used by Winston Churchill to describe his own depression.
- His famous ‘V’ for Victory salute is a symbol that depression can be overcome. In the Institute’s logo, the victory sign casts the shadow of a black dog and provides a metaphor for a disorder that is constantly lurking in the background but that the positive is more powerful than the negative.
- Although spending time talking about mental illness can make people feel uncomfortable, presentations such as this provide a chance to become empowered. Understanding the reality of depression and bipolar disorder means you can be prepared. It means you know where to go for help. And most importantly, you know how to offer hope.

The Black Dog Institute is a world leader in the diagnosis, treatment and prevention of mood disorders such as depression and bipolar disorder.

- Founded in 2002, the Institute combines expertise in clinical management with cutting edge research.

- While research is a key focus of the Black Dog Institute, there is also a real emphasis on teaching people to recognize the symptoms of mood disorders in themselves and others, as well as providing tools to keep depression at bay.

[Anne told us about herself, apart from being a librarian she also likes to visit art galleries, spending time with friends and she absolutely loves shopping. She was diagnosed with bipolar 1 disorder at 20 years of age, which means she experienced episodes of mania followed by a longer episode of depression e.g. mania causes you to lose perspective, the world is like a carnival with bright lights and music everywhere but when depressed that carnival shuts down and she feels empty, dark and alone. Having bipolar has sometimes affected Anne's independence and her relationships but it has also given her something to care about and that is why Anne is passionate about mental health awareness and why she is a volunteer presenter.]

As well as volunteer supporters the Black Dog Institute has a number of high profile supporters who speak publically raising awareness of the destructive consequences of stigma. There are representatives from sport eg Andrew Johns, Nathan and Ben Smith, and the patron of the Black Dog Institute is Professor Marie Bashir, Governor of NSW.

Why Understand Mood Disorders?



Depression: 1 in 7 lifetime prevalence
Bipolar Disorder: 1 in 33 lifetime prevalence



- Depression is prevalent - 1 in 7 Australians will experience depression in their lifetime.
- The number is slightly higher for women, with depression affecting 1 in 6 (17%), compared to 1 in 10 (10%)¹ men experiencing depression in their lifetime.
- Bipolar disorder affects around 1 in 33 Australians in their lifetime.¹ However; prevalence of bipolar disorder is probably higher than the statistics show, as many cases are often undetected or misdiagnosed.
- So, we know that approximately 1 in 7 people will personally experience depression. However, the people in their lives e.g. parents, partner, children, friends, co-workers, carers etc are also likely to be significantly impacted by their illness. For that reason, it is important that everybody is informed, knows what to look out for, and how to help.

[Anne stated how her bipolar affects not only herself but her family and her best friend. She doesn't experience it in isolation, it affects other people in her life.]

Depression and bipolar disorder significantly impact the quality of life of those affected, and the lives of those around them.

- According to the World Health Organisation, depression is the leading cause of disability worldwide. *[Ann always ticks “Yes” when applying for employment when asked if she has a disability because psychiatric disability is a recognized disability.]* In addition, depression is the number one cause of non-fatal disability in Australia (24%).
- Tragically, we also know that suicide is a risk when we are dealing with mood disorders. While this topic is quite confronting, it is important to talk about suicide in the context of illness and suicide is the leading cause of death for people aged 15-44.
- In Australia, we lose more people to suicide than on the roads, yet the level of awareness and information in the community about mood disorders and risk of suicide is far behind what we deliver on driving safely.
- That is why it is so important for people to understand that suicidal thoughts are a symptom of the illness of depression. We need to stop the silence that too often surrounds this topic and prevents people from seeking help.

Normal vs Clinical Sadness

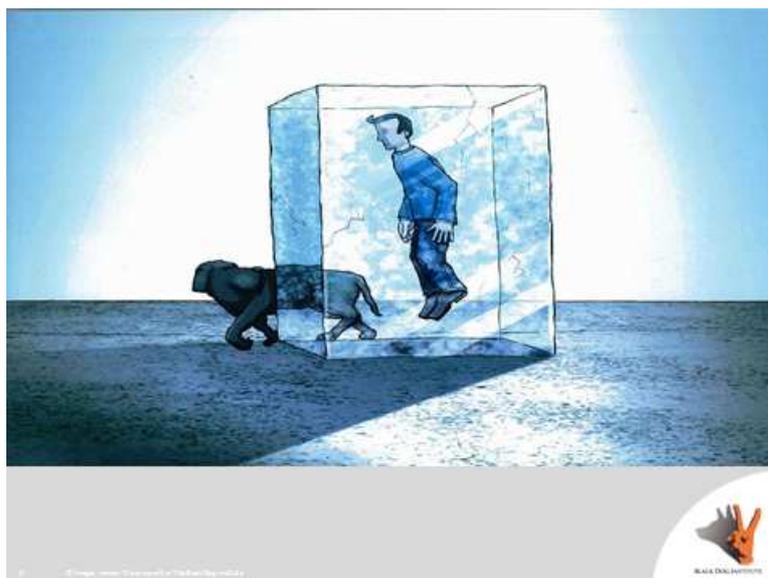
- We know that people can manage depression and bipolar disorder and that treatments are available.
- It is vital to seek help early to avoid longer-term suffering. The first step is learning how to recognise the signs and symptoms, and know when to seek help.



- It's important to remember that mild mood swings are normal. We all experience periods when we feel low or down, have a drop in our sense of self-worth and feel somewhat depressed.
- Experiences such as having a bad day at work, an argument or hearing some bad news can impact on our mood. In turn, self-esteem can be affected, or confidence may be altered – we may even become more pessimistic.

Sometimes we can even feel sad for no reason at all.

- In most cases, people 'bounce back'. However, people with clinical depression can't simply snap out of it and the usual strategies individuals use to lift their mood don't work.

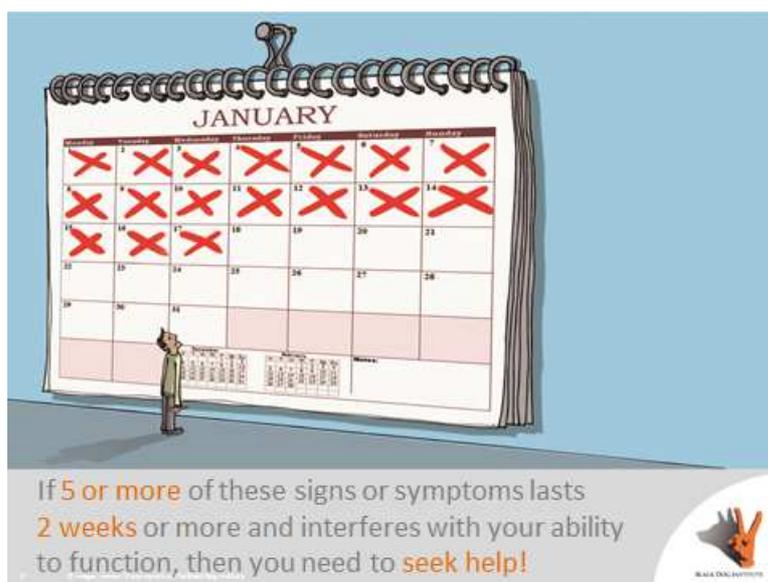


- A person with depression can start to feel quite isolated and withdrawn from the life going on around them. *[Anne stated that she feels frozen in her thoughts and feelings and that no one can reach her.]*



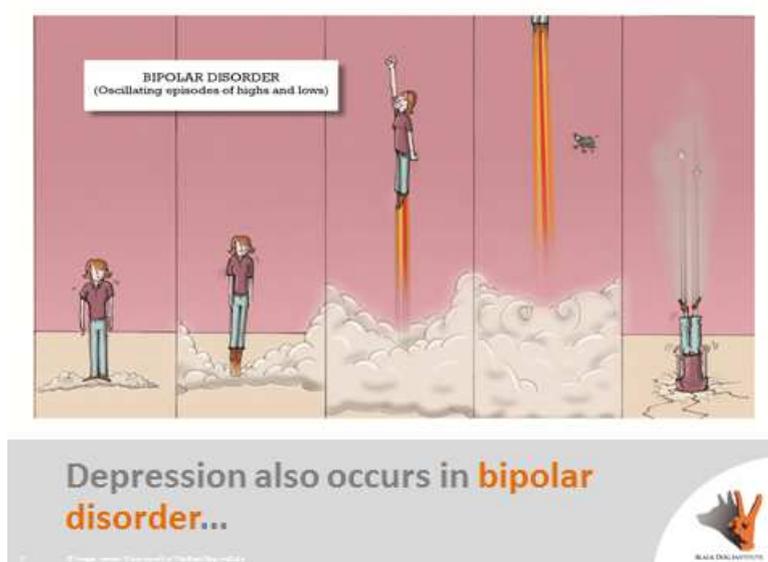
- It can seem as if the 'black dog' starts to follow them everywhere, and starts to take over during the day and into the night.
- It is important to be aware of when normal sadness turns into clinical depression. The main symptoms are:
 - Lowered self-esteem (or self-worth)
 - Feeling hopeless
 - Not able to enjoy life
 - Reduced motivation
 - Sleep, appetite and/or weight changes
 - Less ability to control emotions, such as pessimism, anger, guilt, irritability and anxiety

- Varying emotions throughout the day, feeling worse in the morning and better as the day progresses
 - Changed sex drive: absent or reduced
 - Poor concentration and memory
 - Lowered energy levels
 - Reduced pain tolerance
 - Suicidal thoughts
- Having one or two of these symptoms by themselves might not mean a person is clinically depressed. However, there could be other causes which may warrant medical assessment.



- The general rule of thumb is that if FIVE or more symptoms persist for most of everyday for two weeks or longer and these symptoms interfere with a person's ability to manage at home and at work, then it is time to seek help. We recommend an assessment by a GP or psychiatrist.

Bipolar Disorder



- Bipolar disorder describes the exaggerated swings of mood from one extreme to the other and people with this illness often describe it like living on a rollercoaster.

- Individuals can experience recurrent episodes of high, or elevated, mood (known as *mania* or *hypomania*) as well as clinical depression.
- An episode of high or elevated mood might last for a few days or even weeks.

[When Anne experiences Bipolar Highs she feels like the world is a musical and she is playing the lead role but the problem is that no one else can hear the music because it is all in her head. Life can be quite damaging when you are like this and you do lose your sense of reality.]

- When experiencing a bipolar high, an individual may act in the following ways that are outside their usual character:
 - Loss of inhibitions, reckless
 - Everyone is attractive
 - Acting wired
 - Boundless energy (little sleep)
 - Over-spending
 - Overly talkative
 - Spiritual meaning to everything (Religious imagery)
 - Bullet-proof confidence
 - Solving the world's problems overnight

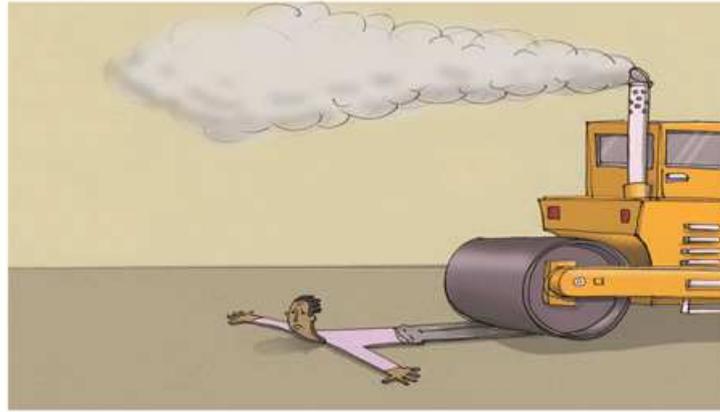
**The different types of
bipolar disorder**

| | |
|---|--|
| <ul style="list-style-type: none"> ▪ Bipolar 1 ▪ Episodes of highs or lows more severe than Bipolar 2 ▪ Psychotic features may be present ▪ Episodes lasting for days, weeks or months | <ul style="list-style-type: none"> ▪ Bipolar 2 ▪ Less severe than Bipolar 1 ▪ No psychotic features ▪ Episodes lasting for a few hours, to a few days |
|---|--|

On-line Self-Test:
www.blackdoginstitute.org.au



- Generally, there are two main types of Bipolar disorder. These are referred to as Bipolar 1 and Bipolar 2. Many people are familiar with the term 'manic depressive'. This term actually corresponds to what we now refer to as Bipolar 1.
- The main difference is the severity of the episodes of highs or lows, with Bipolar 1 being the most severe. Another key difference is that psychotic features (hallucinations or delusions), are also often present in people experiencing a Bipolar 1 episode.
- The important thing to note is that both types respond to treatment and can be managed.



For every big **high**...
...a big **low** tends to follow



- As with the law of gravity, what goes up must come down. We know that while people with bipolar disorder might feel fantastic and productive and on top of the world when they are high, this mood state is not sustainable and an episode of depression is most likely to follow.
- Bipolar disorder also increases people's risk-taking and impulsivity that often leads to negative coping behaviour, such as drinking or substance abuse. The rates of comorbidity for Drug and Alcohol abuse are high for bipolar disorder.

It is interesting to note that bipolar disorder is associated with creativity. There are many 'famous' people who have been associated with bipolar disorder such as Robbie Williams, Britany Spears, Andrew Johns, Abraham Lincoln, Winston Churchill, Jim Carey, Harrison Ford, Princess Diana, Virginia Wolf, Emily Dickinson, Vivienne Leigh, Marilyn Munro and Katherine Zeaiter-Jones.

Causes of Mood Disorders

There are a range of causes of mood disorders:

- **GENETICS:** Mood disorders can be hereditary. Studies of twins shows that there is a genetic predisposition to developing depression and bipolar. What this means is that it is important to start asking questions about the family tree and to know that some people may have a genetic vulnerability. With this awareness, people can be more aware of the signs and be more prepared.
- **STRESS:** Stress can be a major contributor to a mood disorder. [Anne stated that in times when she is quite stressed at work it makes her vulnerable to having an episode.]
- **NEUROTRANSMITTERS AND BRAIN CHEMISTRY:** While our knowledge of the working brain is still limited, research has shown us that there are neurotransmitters, or brain chemicals, involved in mood regulation. One of the chemicals known to play a part in depression is serotonin. It is the dysfunction of this chemical that most antidepressants seek to address.

There are many aspects of depression that are outside of a person's control:

- PERSONALITY STYLES: Research at the Black Dog Institute has also found that personality and temperament can contribute to depression.
- Personality affects the way others relate to you, how you deal with stress and also affect development of support networks and resources to deal with stress. The four Personality Style's that have been found to most correlate with depression include the:
 - Anxious worrier
 - Self-critical
 - Socially avoidant
 - Rejection sensitive
- If you would like to find out more about the links between Temperament and Personality and whether the links may predispose a person to developing depression, a Questionnaire is available on our website.

Living with the Black Dog

- While the lists of symptoms are useful in detecting depression, they do not really capture the lived *experience* of the illness.
- In 2007 we held a writing competition on 'living with the black dog' and received many rich descriptions of what depression actually feels like (compilation of 634 entries).
- Analysis of these stories shows that some of the most common metaphors used to describe the black dog are:
 - Dark cloud
 - Pit
 - Malevolent entity
 - Devil or beast
- People commonly express feelings of being trapped, isolated, hopeless and alone and these descriptions illustrate that experiencing depression is much more than only physical problems related to sleep or appetite.

[Anne added that some of the descriptions received related to depression as a mood disorder but also something physical in terms of people were often losing sleep or their appetite as well. "I faded away to a shadow of my former self; it's a savage disease that destroys your very soul and the essence of your being. Depression takes away the one thing that you thought could never be taken, yourself. "]

Fears of Seeking Help

- Although there are ways to seek help and support someone else, it's not always easy to encourage another person to seek help. Fear and stigma are often barriers to overcome.
- Sometimes people have a fear that they'll be perceived as weak, but if we can increase our mental health literacy, we can understand that seeking help and speaking up takes courage and is actually a sign of strength.
- There is also the fear of being labelled or called names, but with more education and understanding, we can also have more empathy.



- Many people are misinformed about the need for medication and fear seeking help in case they are prescribed medication. Also, some people fear the side effects that medications may have, but it is important to know that not everyone needs medication.
- For some people, there is also a fear of being hospitalised. We've all seen movies where people are in strait jackets in chaotic or terrifying mental hospitals, but that's Hollywood – not reality!

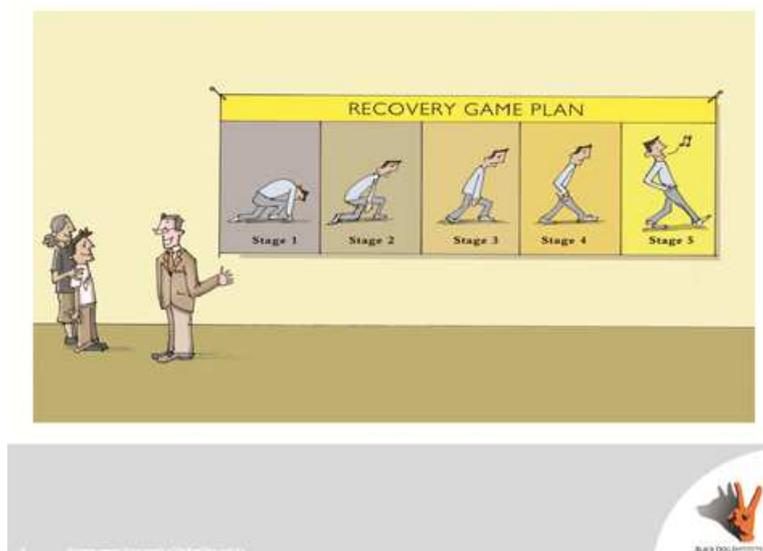
How to Seek Help

- 65% of people with mental illness don't access any treatment but ignoring the situation and hoping that symptoms/problems will go away is not effective.
- When worried about yourself or someone else, the first step is quite straightforward - see a doctor. A GP will provide an assessment that includes a general check-up to see whether there are any physical causes to the symptoms, and assess the nature of the mental health problem.
- The GP may make a referral to a psychiatrist, or suggest counselling. GPs can now also refer people to psychological services and sessions with an exercise physiologist and claim a Medicare rebate.
- Depending on the severity of a person's depression, some medication may be prescribed to relieve symptoms.
- It is worth booking a long consultation, as it can take time to explore all the issues associated with making an accurate diagnosis.
- It's also important to know that, for various reasons, the first GP a person visits may not be right for them. It is important to feel comfortable talking with a doctor and a person should expect time, confidentiality, good communication and empathy.



[Anne explained that The Black Dog Institute has a mood assessment program. There are also GPs who have undertaken extra training in Better Outcomes in Mental Health Care (this training program was developed by the Black Dog Institute), so ask if your GP has had this extra training, it shows that they have an interest in mental health issues and it certainly makes a difference if they do.]

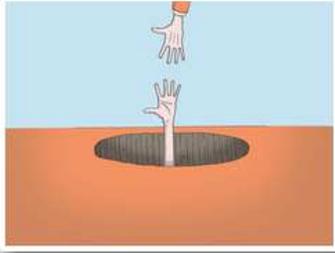
- The Black Dog Institute has several clinics that are open to people over the age of 16 with a Medicare card.
- All of the Black Dog Institute clinics are specialist treatment services and don't take over the ongoing case management of patients. Case management will remain the responsibility of the referring health professional.
- There are also no in-patient services and referrals are essential to make an appointment.
- Find out more from the Black Dog Institute website: <www.blackdoginstitute.org.au>.



- But whoever you see – whether psychiatrist, psychologist, counsellor or social worker - make sure they have a recovery game plan, as it will give you something to work towards and an understanding of when you can expect to feel better.

Helping Others

Suggestions for helping



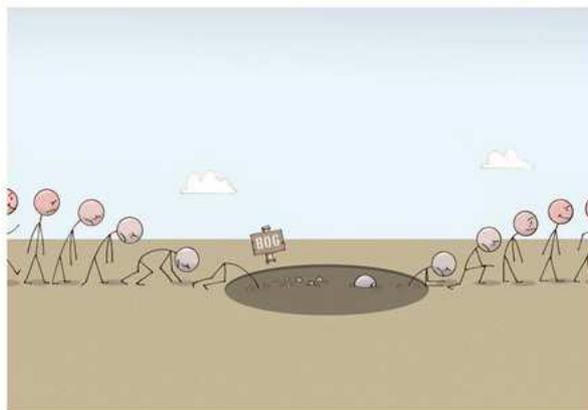
- Gently let them know what you have noticed and why you are concerned
- Create space
- Listen first
- Take things at their pace
- Respect their point of view
- Offer warm support
- Validate



- One of the most common questions we get asked is, how do you help someone else?
- This is the hardest question to answer, as unfortunately, you cannot help someone who doesn't recognise they have a problem, or need help.
- If you are worried about someone else, just start by creating space to talk.
 - Gently let them know why you are concerned.
 - Encourage them to open up.
 - Listen.
 - Take things at their pace.
 - Respect and VALIDATE their experiences.
 - But remember, you cannot make someone get help, until they are ready.

[From Anne's point of view, her friends ask her – “Are you OK”, “how are you”, “how is your bipolar disorder”. A good friend should ask, don't be afraid to ask what is wrong.]

Understanding Resilience



- Resilience starts with accepting what you can and cannot change. For example, you can't change the weather but you can change how you look at and deal with it.
- It's the same with your life: you can't change your past, your upbringing, and so forth, but you can change the way that you look at and feel about your history.

- You have a choice **how** your history makes you who you are today.
- Resilience can be described as our ability to face, overcome, and even be strengthened by the challenges of life.
- Building resilience is about getting through things, being better for it, and appreciating life.
- Resilience has 6 domains you can build on:
 - Physical
 - Social
 - Cognitive
 - Emotional
 - Moral
 - Spiritual
- So how do we build resilience? It's not something we're born with – we need to learn and build it.
- Building resilience can help prevent mood disorders.



[It is recognised that exercise is of course an issue for most polio survivors.]

- Exercise Your Mood: The level of physical health and well-being impacts on our capacity for resilience.
- Research suggests that regular exercise may increase our body's natural chemicals (*endorphins*) that affect mood, sleep, libido, appetite and other functions.
- Aim for at least 30 minutes of brisk walking or some form of activity where you notice a slight increase in breathing and heart rate (as recommended by the National Physical Activity Guidelines for Australians).
- Eat Good Mood Food: Physical health also includes a healthy diet, regular meals and adequate sleep.
- Eat a balanced diet and have minimal processed foods, sugars, coffee and energy drinks.

- If you are interested in foods that can positively affect your mood, check the Black Dog Institute's online Fact Sheet about Omega-3 (fish oil) benefits



- Good relationships are also really important for building resilience, so it is important that you put into your friendships what you expect in return – love, support, respect. These are all things that you can expect from people, especially your friends.

[For Anne having people she can talk to and have fun with, people who inspire her and challenge her is vital to living with bipolar disorder. She stated that she honestly could not survive without her friends because they make her world a better and a more hopeful place and she hopes she does that for them in return.]

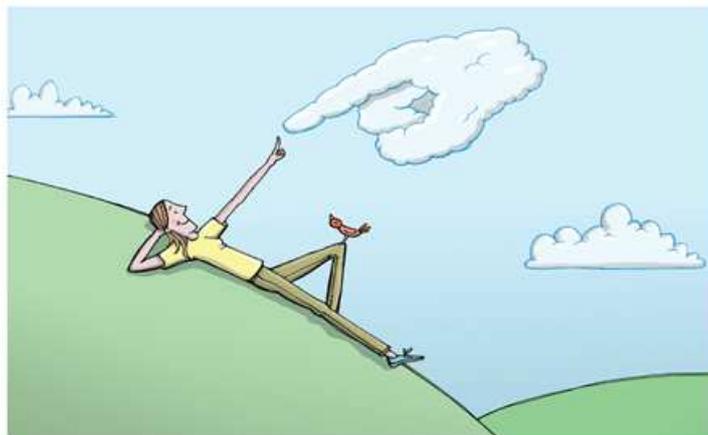
- Be the Gate Keeper of Your Thoughts: The way you think about things can affect your level of resilience.
- When you have negative and unhelpful thoughts, become the 'Gate Keeper' of your thoughts by holding the key to them.
- Only you can change the way you think about things.
- You can also learn good problem-solving, goal-setting and time-management skills. Acknowledge your successes and praise yourself for your achievements.
- Keep a Level Head: Maintaining a level-headed approach to dealing with everyday stresses is another path to building resilience.
- It's easy to go off the rails when you're confronted by stressful events, but how you respond to life's challenges can influence your mood and outlook.
- One of the easiest and most effective ways to build resilience is to regularly practice slow breathing.
- Research has shown that slow breathing can also lower blood pressure and heart rate, reduce stress hormones, improve immune system functioning, increase physical energy and feelings of calm and wellbeing.



Help others!



- Connecting with others and contributing to a bigger picture is part of building resilience.
- Resilience can be built by contributing to family, social groups, and to the wider community.
- Perhaps you might like to volunteer! Helping others can help you tremendously as the simple act of giving has the biggest returns.
- It is also important to have a set of values or guiding principles. Your values are reflected in the decisions you make and what is important in your life.



What gives you **meaning**?

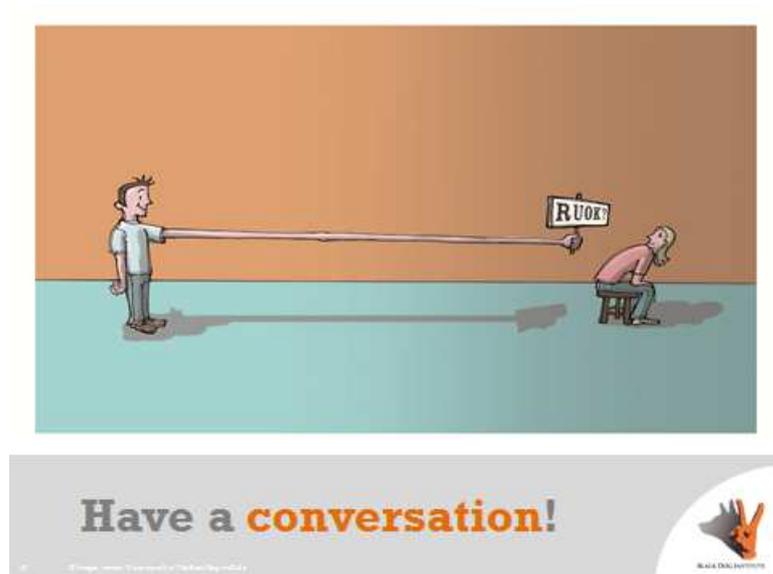


- Having a spiritual dimension to our life can also make us happier and more resilient.
- Spiritual wisdom doesn't need to involve myth and mysticism; nor does it necessarily have to be linked to organised religion, although people with strong religious faith often experience high levels of wellbeing.
- Spirituality can provide us with meaning and connect us to 'something bigger' beyond our daily life.

- You could build resilience in this way by identifying things in your life that give you a sense of meaning and purpose – your faith, family, hobbies, school, work, the environment ...



- Building resilience is important and it probably sounds obvious but everyone can take the time to be more mindful and appreciative of big and little things in life like:
 - The taste and smell of a hot cup of coffee
 - The sun on your face
 - The warm water on your back in the shower
 - The joy and innocence of a small child
 - The love and loyalty of pets
 - Being in nature



- I hope you've got a lot out of this presentation and remember that if you only take one message away from today it is this: have a conversation with someone you are worried about and seek help if you are concerned about your own mental health.

www.blackdoginstitute.org.au

Mid-Year Seminar - 23 July - Preliminary Information

by Anne O'Halloran, 2014 Seminar Co-ordinator

Our mid-year one-day Seminar will be held on Wednesday, 23 July 2014, at the Northcott Conference Room, Ground Floor, 1 Fennell Street, Parramatta. The day starts with registration at 9:30 am and proceedings will wrap up around 3:00 pm. The registration cost of \$10 is subsidised by Polio NSW and includes morning tea and a light lunch. We are very pleased to have secured three excellent speakers to present on a range of interesting topics.

Ms Jenny Ly, Senior Health Promotion Officer, Arthritis and Osteoporosis NSW

Jenny's presentation will draw upon her special interest in complementary medicines and health education.

Mr Robert McLeod, Chief Executive, Sydney Cochlear Implant Centre (SCIC)

SCIC is a charity that provides cochlear implant services at little or no cost to deaf children and adults. Robert will speak about what is involved with cochlear implant for people with hearing impairments.

Emeritus Prof Barry Baker, former Professor of Anaesthetics, Sydney University

Barry has a keen interest in the history of medicine. His presentation will include some history of the polio epidemics and early treatment, and provide insight into the place that polio played in the formation of hospital intensive care units. He will also discuss issues of current management for polio survivors, particularly during surgery and anaesthesia.

Further information on the speakers and their presentations will be included in the next issue of *Network News*.

Polio Post



It is always nice to receive updates from our members. The following is from Dorothy Robinson, Convenor, Wollongong Support Group.

At our February meeting, eleven people were in attendance with one apology from Jim Widdicombe. We met for lunch and those attending included a most welcome new member, Helen Falconer, who came with Bill and joined regulars Bob and Doreen Gregory, Gordon and Thelma Knight, Bill and Pat Phelan, Fay and John Powell, and myself. We all enjoyed each other's company and talk covered too many topics to keep track of but did include polio, shoes, vaccination and the upcoming Retreat. Dorothy.

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 Polio Australia: www.polioaustralia.org.au



2014 Polio NSW Activities

| | | |
|---|---|--|
| Thursday 8 to Sunday 11 May 2014 | St Joseph's Baulkham Hills Centre for Reflective Living | Polio NSW will host Polio Australia's 2014 Polio Health and Wellness Retreat See pages 2 and 3 |
| Wednesday 23 July | Northcott Building 1 Fennell Street Parramatta | Preliminary information is on page 22 Final details in the next <i>Network News</i> |
| October 2014 | <i>Venue to be advised Canberra</i> | <i>Date and venue being determined Program and speakers to be advised</i> In conjunction, we also hope to hold a Support Group Conveners Workshop |
| Saturday 29 November | Burwood RSL 96 Shaftesbury Road Burwood | Annual General Meeting 25th Anniversary Lunch End-of-Year Seminar |

Management Committee – Executive Members Contact Details

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

PPN Office and Other Contact Details

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| Gary Fuller | Support Group Co-ordinator | support@polionsw.org.au | 02 9523 2428 |
| 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 |

About Polio NSW

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

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

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

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

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

Resources for Members

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

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

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

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

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

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

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

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