



POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS



Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

First and foremost, on behalf of the Management Committee, and particularly the Treasurer, I would like to sincerely thank all those members who have renewed their memberships very promptly, and so often accompanied by generous donations. As advised in my recent letter to members, the difficulties we have had in raising sufficient revenue to keep our office operations going at a sustainable level and at a standard that provides the information and advocacy services members expect, led to the hard decision to increase membership fees (albeit for the first time in 15 years). Treasurer, Alan Cameron, writes: *"I want to specifically thank those who donated a little more, and really thank those of you who are finding life financially pretty tough who have renewed membership at the new changed fees. It might not be the whole long-term answer to the future of Polio NSW but the preparedness of you the members to help in sustaining our organisation is really appreciated."*

Our mid-year Seminar held on 3rd June was very successful with around 40 members and friends learning more about retirement living choices from informed presenters. The Seminar Report is under preparation and will appear in the next issue of *Network News*.

On pages 2 and 3 you can learn more about the Assessment Clinic set up by Mt Wilga Private Hospital for people who have the late effects of polio. This monthly one-day clinic includes a Medical, Physiotherapy, and Occupational Therapy assessment under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie. Dr Mackie has reported that the Clinic is proving to be very popular with members, so book now as the wait time for an appointment is increasing.

It is time for our annual "Walk With Me" fundraising event which is run in conjunction with Polio Australia – 50% of the funds raised come to Polio NSW. Last year we received almost \$6,000 from our Parramatta Walk, held in partnership with the Northcott Society. Details of the 2015 Parramatta Walk, to be held on 16 September, appear on page 4. Polio Australia President and Polio NSW Committee Member, John Tierney, has provided helpful fundraising tips on page 5. Even if you are unable to make it to Parramatta, you can still help make this year's Walk successful by encouraging your family and friends to donate in support of the "Polio Power Parramatta" team – donations to the team (www.walkwithme.org.au/event/wwmwesterndnsy2015) will be open until 31 December.

This year, for the first time, Polio Australia is also holding a Walk in Canberra, to be held on 15 October during Polio Awareness Month. Parliamentary Patrons and Friendship Group members will be participating with us as the "Polio Power Canberra" team walks around Parliament House. Again, donations are open until 31 December and the funds raised will be shared with Polio NSW. Go to <www.walkwithme.org.au/event/wwmcanberra2015> to learn more.

While on the subject of Polio Awareness Month, we have enclosed some flyers with this newsletter to help you to help us promote the existence of Polio NSW and our services for polio survivors.

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Living Your Best Life

Mt Wilga Private Hospital and Polio NSW are excited to announce the formation of a dedicated Assessment Clinic for people who have the Late Effects of Polio (LEoP).

The LEoP Assessment Clinic is a one day clinic, held monthly, and includes a Medical, Physiotherapy, and Occupational Therapy assessment under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie.



Dr Mackie is the past President and current Medical Adviser to the Australasian Lymphology Association (ALA). Dr Mackie is a Rehabilitation Specialist at Mt Wilga and is passionate about the early detection screening of patients who are susceptible to Lymphoedema. Dr Mackie also works with patients in the long term management of Lymphoedema at Mt Wilga and is the Clinical Lead at the Advanced Lymphoedema Assessment Clinic (ALAC) at Macquarie University Hospital Clinic.

Dr Mackie has an ongoing interest in musculo-skeletal rehabilitation, pain management and general rehabilitation medicine. Dr Mackie is also an Examiner for the Faculty of Rehabilitation Medicine.

What are the LEoP?

Poliomyelitis or Infantile Paralysis is a viral infection that was common around the world until the early 1960s, with the last major outbreak in Australia in 1956. The polio vaccine was introduced in Australia in 1956 and was followed by mass immunisation programs.

Before mass immunisation in Australia, it is estimated that a minimum of 40,000 people contracted paralytic polio in Australia between the 1930s and 1960s, whilst up to 4 million people contracted the virus with only minor symptoms.

Unfortunately, today in Australia, thousands of Australians now experience what is known as the Late Effects of Polio (LEoP).

How do I know if I have the LEoP?

You may experience one or more of the below symptoms which are common to people who have the LEoP. You may have even developed some of these symptoms much later on in life after you contracted the initial infection, even if you had few or no symptoms at the time.

It is also important to know that not all of these symptoms may be directly related to LEoP but are a cause of another condition like osteoarthritis. However, if you have any of these symptoms we recommend you attend the LEoP Assessment Clinic.

- Unaccustomed fatigue (either muscle fatigue or feeling of total exhaustion)
- New muscle weakness (including muscles apparently unaffected at the time of the initial infection)
- Joint and/or muscle pain
- Sleeping, breathing or swallowing difficulties
- Increased sensitivity to cold temperatures
- A decline in the ability to perform basic daily activities

Do I require a GP referral to be a part of the LEoP Assessment Clinic?

Yes, please ask your GP or other specialist to fax a referral to Dr Helen Mackie on **(02) 9847 5013**. Once we have received your referral, Dr Mackie's secretary will telephone you to make an appointment for assessment.

If you would like any more information, please contact Dr Mackie's office on **(02) 9847 5085**.

You will also be sent a medical questionnaire that we would like you to complete and fax back on **(02) 9847 5013** prior to your assessment.

Do I need private health insurance to attend the LEoP Assessment Clinic?

No, you can discuss with your GP about approving a Chronic Disease Management (CDM) Plan, formerly known as the Enhanced Primary Care Plan, which provides Medicare rebates for Allied Health services to people who have a chronic disease. Otherwise you may wish to self-fund the Assessment Clinic.

If you have private health insurance, this clinic will be considered an outpatient visit and you will need appropriate extras private health cover.

To obtain a quote on Assessment Fees, please contact Dr Mackie's office on **(02) 9847 5085**.

What happens after I attend the LEoP Assessment Clinic?

At the completion of the clinic, we may provide you with an individualised exercise program prescribed by your Physiotherapist, recommendations by your Occupational Therapist to manage your activities of daily living easier, and provide referrals or recommendations to community based services which may be applicable to your situation.

If you have private health insurance, we may recommend you participate in an individualised day program at Mt Wilga. We will, of course, make sure your private health fund covers you for our day therapy program prior to your commencement and advise you of any gap in funds.

Your day program may be for four to six weeks depending on your requirements and may cover other services including dietetics, speech pathology, psychology, exercise physiology as well as physiotherapy and occupational therapy.

A fortnightly case conference will be held with your Rehabilitation Physician, Dr Helen Mackie, and other members of your allied health team, to discuss your progress – they may refer you for further therapy if appropriate.

Where does the Assessment Clinic take place?

The Assessment Clinic is at Mt Wilga Private Hospital, a specialist dedicated rehabilitation hospital and Day Therapy Centre. The address is:

66 Rosamond Street
Hornsby NSW 2077
Main reception (02) 9847 5000

There is plenty of free parking available on site, and off-street parking as well.

www.mtwilgaprivate.com.au

Will you...

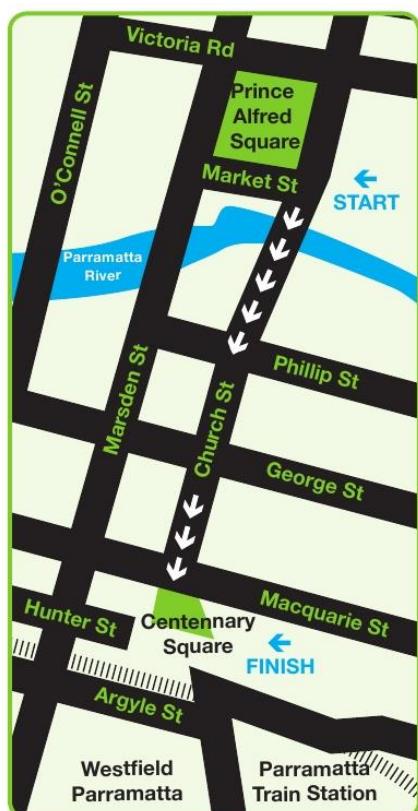
Walk With Me

dick smith
dicksmith.com.au



A short walk for some can be a challenge for others. Join as one community, walk side by side with people with disability, raise awareness and support a world where all are truly included.

Parramatta - Wednesday 16 September, 2015



How to get involved:

- Walk with your friends, family, colleagues, clients
- Express yourself! Pick a theme, design a banner, create a float
- Encourage and support others to attend
- Promote the event any way you can

When:

Wednesday 16 September, 2015

Time:

Meet for walk at 11am, entertainment, information and food stalls between 12pm - 2pm

Where:

Meet at Prince Alfred Square and walk down Church Street to Centenary Square (near Parramatta Town Hall)

In partnership with

Northcott
supporting choice & opportunity



For more information contact:
Gillian at <gillian@polionsw.org.au>
or Polio NSW Office at 02 9890 0946

To Walk with or Donate to the "Polio Power Parramatta" Team, or to register your own Team of Walkers, go to: <www.walkwithme.org.au/event/wwwwesternsyd2015>.

How to "Walk With Me" in 2015

by Dr John Tierney President and National Patron of Polio Australia

We can raise even more money to support polio survivors in NSW

"Walk with Me" was a great success in 2014 raising \$16,670 across Australia for polio survivors. Walk With Me has become Australia's polio organisations' top fund raising event.

I became the top fundraiser across the whole of the *Ability First Australia* network, raising \$9,180 dollars by applying a few 'tricks of the trade'. These are easy techniques that you can use this year when you take part in "Walk With Me".

The reason that I raised a lot of "Walk With Me" money in 2014 was because of the way in which I approached potential donors. So, I have outlined a few tips below.

You have the best chance with people you know really well, so draw up a series of lists under the following headings:

- your family
- personal friends
- polio survivors that you know
- family and friends of other polio survivors that you know
- work mates
- fellow volunteers
- local community members that you know really well
- others?

When you have completed your list, you should talk, one-on-one or by phone to your potential donors.

However, if you prefer to write:

- draw up a template email / letter that will form the basis of what you sent out, and
- personalise the individual email / letters as much as possible and use their first name in the text.

Also, for the ones that you ask and who don't respond, send them a 'reminder note' just before you do the Walk. You should also let them know that donations will still be accepted well after the event.

Please remember to:

- just look a bit wider in your search for people who might be prepared to donate to "Walk With Me",
- prepare personalised notes, and
- have a follow up strategy.

If you do all of this, I am confident that your fundraising for "Walk With Me" in 2015 will be even more successful!



MEMORIES OF COLLAROY CONVALESCENT HOME 1954

By Susan Stewart, May 2015



I contracted polio in December 1953, aged 11, and was sent by ambulance from our home in Bundanoon to The Children's Hospital at Camperdown.

Sometime before February 1954 I was moved to the Convalescent Home at Collaroy. I had severe paralysis of my left leg and some weakness in my right leg and left arm.

I was in a large ward in a big iron bed with pull up sides which was wheeled out onto the front veranda when the weather was pleasant. My legs were both bandaged into splints, and no one was allowed to get out of bed unless we were having our daily session with the physiotherapist when our splints were taken off, boots and calipers fitted and walking tuition began. Crutches and calipers first, then calipers only.

The hardest part was no visitors were allowed except on Sunday afternoons. Apparently it was thought to be too upsetting for the children, but it was especially hard for my family who had to travel for several hours for a short visit once a week.

We had occupational therapy too – beads, puzzles, craft, lots of reading, and eventually my parents enrolled me in "Blackfriars Correspondence" and I got a folder in the post every fortnight with lessons set out, which I had to post back and receive comment in the next packet. My favourite time was Saturday afternoon when "Brown Owl" from the local Girl Guides came and we were regular guides – in wheelchairs. The above photo is when I was formally inducted into the Girl Guides.

In February 1954 during the Queen's visit to Sydney several of us were taken by ambulance, organised by the Crippled Children's Society, to Government House where we sat in wheelchairs in the garden and waited for the Queen and Prince Phillip, who on returning from an official function came over to give us a wave. It was very hot, and I had on my first "best dress" which had been ordered for this special occasion. It was delivered to Collaroy from David Jones in a big box with layers of tissue paper! A wattle yellow organdie dress with lots of tiny covered buttons and a big lace collar.

Later in the year, I unfortunately was very ill with infectious hepatitis, and was immediately transferred to The Coast Hospital at Little Bay. I was the only child in the female ward which was quite frightening at first, but gradually the other patients were friendly and very kind – no visitors of course, and no physiotherapy either. As soon as I was well enough, my parents decided it was time to take me home. I don't recall the exact date, but it was winter in Bundanoon, and I've always been told I spent six months in hospital.

In retrospect, I was one of the lucky ones. I had weekly physiotherapy for the next couple of years and was able to overcome all weakness except for my left leg. With today's superior orthotics, I have replaced the dreaded "irons and boots" with a synthetic spiral caliper which my grandchildren call "Nana's spare leg". Swimming has helped me keep reasonably fit, and I can even play golf with the help of a cart.

As a mature post-polio sufferer, I learned a lot from my association with the Polio NSW Inc network, not least of which has been acceptance and determination to make the most of what I can do, and not to regret my physical limitations.

Vale: Barbara Ann Fuller 30th December 1934 - 6th May 2015



Barbara Fuller

It is with great sadness that we advise of the passing of Barbara. She is greatly missed by our Committee members. Barbara and husband Gary were Polio NSW Support Group Co-ordinators and were so enthusiastic and caring in their role.

A number of our members attended the "Celebration of Barbara's Life" on 14th May at Woronora Crematorium.

Gary and Barbara shared 64 years together, raised three sons, Steven, Michael and David, and proudly enjoyed their eight grandchildren Sam, Andrew, Alexia, Jack, Phoebe, Henry, Ashley and Sienna.

Young Love in the Time of Polio

The Golden Age, by Joan London. Review by Joan Hume, President, Spinal Cord Injuries Australia.
Reprinted from ACCORD, Autumn 2015



Summertime in Perth in the early 1950s struck fear in the heart of every parent, as it did in the rest of Australia's towns and cities.

From the 1930s till the 1960s, virulent polio epidemics swept almost randomly throughout our communities usually in the warmer months and mostly children were the targets.

Until the advent of the Salk and Sabin vaccines from the mid-1950s which virtually wiped out polio in Australia, the disease caused widespread panic, and irrational bigotry against and the social isolation of survivors and their families.

Contagion's grip

Polio (poliomyelitis), also known as infantile paralysis, is a highly infectious viral disease, spread from person to person through the mouth and thereafter multiplying in the intestines.

The virus can then invade the brain and spinal cord. It usually paralysed the legs but could also paralyse the respiratory nerves and upper limbs and in some cases result in death.

According to Polio Australia, between the 1930s and 1960s there were 40,000 cases of paralytic poliomyelitis recorded in Australia, but the total number of polio infection cases may have been up to 100 times greater. This is because only one in 100 cases of poliomyelitis caused paralysis thereby requiring hospitalisation and mandatory reporting.

It is against this background of post-war Perth in the grip of the polio contagion of 1953-54 and the imminent first visit to Western Australia by the young Queen Elizabeth and her husband that Joan London's novel "*The Golden Age*" is set.

Life in the old pub

The Golden Age is an old pub converted into a children's convalescent and rehabilitation centre where fourteen paralysed children have been sent after hospital to learn to walk and live independently again.

Here we meet 13-year-old Frank Gold, the only son of Jewish Hungarian émigrés swept away from their cultural and familial roots by a vicious war to the other side of the world. Frank is intelligent, perceptive, a budding poet and mad for Elsa, a fellow resident. Elsa is 12, a beautiful, gentle and serene observer of this insular and highly regulated world under the benign and watchful care of head nurse, Olive Penny.

All of the children form strong, loving bonds; however, the growing secret passion between Frank and Elsa and the aftermath of its shocking discovery is the pivot on which the narrative turns. In the book, sexual love between such young people with disabilities is as tacitly forbidden as it is unthinkable. Even disgusting.

The skill of the writer lies in conveying the truth of the children's wisdom and maturity beyond their years, wrung from the grief, loss and devastation of sudden and disfiguring disability.

Ripple effect

Interwoven with the central story are the lives of the children's families and their varying reactions to how polio has forever begun to reshape their destinies for better or worse. This is handled with great delicacy and insight. As these families from disparate social background come together around the rituals of visiting and fund raising for the centre, tentative friendships are struck in mutual need.

From these events the novel offers a poetic reflection on more universal themes of nostalgia for a lost past, exile, belonging, bereavement and ultimately self-acceptance. Frank and Elsa's fate could be anyone's such is the cruel randomness of a polio epidemic or a car accident.



EnableNSW

Reprinted from Spinal Cord Injury Australia newsletter, Accord, Summer 2015.

The NSW Health Department operates and manages EnableNSW, which provides health, medical and equipment programs to support people with disability and people with health and medical conditions to live in the community. EnableNSW management hosted a number of briefings for non-government organisations (NGOs) representing the disability and community sector.

The briefings were particularly for NGO staff who support EnableNSW clients with individual advocacy, as well as staff who work in policy and systemic advocacy. SCIA Policy and Advocacy representatives attended both sessions which were held at the EnableNSW Parramatta head office.

The briefing agenda was to provide answers to questions raised by NGO staff about the following: equipment and service waiting and processing times; implementation of person centred approaches; EnableNSW's involvement in the National Disability Insurance Scheme (NDIS) trial; equity of access; complaint handling; stock equipment and standardised purchasing; and Commonwealth Home Care Packages.

EnableNSW's briefing also discussed the plans to update the EnableNSW program information. This included opportunities for seeking feedback from participants in other areas, such as consumer information priorities, website redesign project, program guidelines, equipment procurement, and identifying and removing barriers.

Regarding equipment and services, EnableNSW operates a number of programs, including the Aids and Equipment Program, Prosthetic Limb Service, Away from Home Haemodialysis (AFHH) Program, Statewide Paediatric Equipment, Home Respiratory Program, and IPTAAS – Travel Assistance.

Soon after EnableNSW administration was centralised to the Parramatta head office about five years ago, the streamlining of the administration and unifying of the policies and procedures created some financial savings and reduced the waiting times to receive equipment. But it seems the honeymoon is over, and it was reported that there is a shortfall in funding that has resulted in a blowout in waiting times for some of the programs.

As of November 2014, there was approximately \$15 million of unfulfilled applications across all EnableNSW programs. However, the majority of the unfunded items are in the Priority 2 classification (aids and equipment), such as wheelchairs, where there is a waiting period of seven months. Priority 1 items (aids and equipment), such as lifting hoists, adjustable beds, pressure care mattresses, etc have a three month waiting period. The prosthetic Limb Service has no waiting list.

SCIA Policy and Advocacy appreciates that EnableNSW has been very proactive in working with the community and disability sector. And we look forward to providing comment and feedback on the EnableNSW resources being developed, such as the aids and equipment procurement process.

Notwithstanding these outcomes, SCIA Policy and Advocacy is acutely aware of the urgent need for greater funding for EnableNSW's programs, and it will continue to advocate for funding to meet consumer needs and reduce waiting times.

To discuss any EnableNSW issues, email <policyteam@scia.org.au> or phone toll-free 1800 819 775.



Update on Anesthesia by Selma H. Calmes

Reprinted from Post-Polio Health Vol. 31, No. 1 Winter 2015, at <www.post-polio.org>

Dr Selma H. Calmes, MD, Retired Anesthesiologist, Culver City, California

Presented by Dr Calmes at PHI's 11th International Conference on June 2, 2014, in St. Louis

Many polio patients fear anesthesia. Multiple surgeries in childhood were common for those who had polio, and anesthesia care then was not as sophisticated as it is today. Modern anesthesia is much improved since the time of polio epidemics! I have been asked, as a polio survivor and an anesthesiologist familiar with modern anesthesia practice, to answer recent, common questions asked by post-polio patients.

Do I really need to have a colonoscopy? It requires anesthesia, and I'm afraid of that.

Colon cancer is the third most commonly diagnosed cancer and the third leading cause of death from cancer in the United States. About 5% of Americans will be diagnosed with colon cancer in their life-time. Colonoscopy (looking at the lower part of the intestine with a flexible telescope, to identify early/possible colon cancer) is currently the most accepted way to identify early colon cancer; it has been well-documented to save lives because early lesions can be identified and removed.

Newer tests (virtual colonoscopy, stool DNA mutation tests and immune-chemical Fecal Occult Blood Tests (FOBT) have been developed recently, but only virtual colonoscopy has been compared with colonoscopy. It compares favourable, but it is not possible to treat lesions found. If lesions are found, you must still have a regular colonoscopy. There may also be problems with insurance payment for virtual colonoscopy.

- Colonoscopy is recommended for everyone over age 50 years, earlier if you have a family history of colon cancer or other risk factors. You must have a bowel prep, to remove stool so the endoscopist can see lesions, and anesthesia (sedation) is usually given for patient comfort – bowel inflation with gas, to distend the colon, is needed, and is uncomfortable.
- You need to commit to getting screened somehow for colon cancer. Which screening is best depends on you and your MD's experience. Colonoscopy should be done by an experienced Board Certified gastroenterologist, in a certified outpatient facility. The risk of anesthesia is small compared to the risk of colon cancer.

Why is it so hard to link up ahead of time with the anesthesiologist who will handle my case?

Daily anesthesia staffing is a complex equation. It is extremely difficult to know ahead of time who will be doing which case on a particular day. There is a constant flux of anesthesia staff (people get sick), other needed staff such as techs, incoming emergency cases, obstetric anesthesia cases, cases may move from one operating room to another for equipment or staffing problems, and so on. And, anesthesia group size is increasing; it is not unusual to have groups of over 100 anesthesiologists.

So, what can you do, given these problems? Two helpful possibilities follow:

If at all possible, try to have your operation at a major university hospital.

This gives the best chance of getting quality care (not only anesthesia care). Check its accreditation data on the Joint Commission for the Accreditation of Health Care Organization's website. Many states also have hospital quality data on the web. Most academic hospitals also have pre-operative clinics in which patients are screened ahead of time. These are extremely helpful in identifying and preparing for difficult patients. They also have an array of expert physicians in many areas. Especially important here is ICU care and MDs capable of handling respiratory failure postoperatively.

Use your surgeon to lead the way to the anesthesia department.

Surgeons and anesthesiologists work together daily and often become "teams", making it easier for them to work together on a difficult patient. When an operation is being planned, explain your post-polio issues (scoliosis, pulmonary failure and a history of iron lung use are red flags here) and ask that they be noted during scheduling and also if the surgeon could speak with the anesthesia department ahead of time, to warn anesthesia staff you are coming and what the issues are.

What's new in anesthesia that I need to know?

This is a brief listing:

- Better measurement of quality of care in anesthesia and better recognition of where problems are and how they could be improved.
- Increasingly sophisticated knowledge of ventilation problems and better management of respiratory problems post-op.
- Recognition that many patients are left with residual neuromuscular block and the possible complications.

- The desirability of using both regional anesthesia and general anesthesia together, for improved outcome.
- Does the medical literature document anesthesia problems for post-polio patients? A 2013 review found no unusual problems and that regional anesthesia was not reported to cause worsening of PPS.

What are the issues in bariatric (intestinal surgery that can facilitate weight loss) surgery for post-polio patients?

This sounds like a “quick fix” for obesity but is an area full of possible problems. There are no reports of post-polio patients having bariatric surgery.

Possible problems relate to the disease obesity (diabetes, presence of sleep apnea, presence of a fatty liver, the increased difficulty of anesthetizing obese people), where the procedure is done (outpatient facility/in a hospital), the procedure done (lap band or gastric bypass) and who does the operation.

Lap bands (placing a flexible plastic band with an injection port around the upper stomach and inflating the band as needed) sounds simple and quick, but the bands can have complications and may need to be removed.

Best results come from dedicated teams, including a dietitian, at academic medical centers. Long-term follow-up is essential!

**You can read more about anesthesia by Dr Calmes at
www.post-polio.org/ed/majtop.html**



The following article was written by Fran Henke, a member of Polio Network Victoria. It originally appeared in Inform, Polio Perspectives, Easter 2015. It is reprinted here with Fran's permission.

Now ‘retired’ Frances Henke is a journalist and author aka Frances Kelly and George Davis. As Frances Kelly she has written 14 books, on gardening and local history. Her work has been included in four ‘best of’ anthologies of garden writing and journalism; she is a published poet and an artist.

Obituary: Stella Young by Fran Henke



“Stella Young – Chair way to Heaven”

Fran’s tribute painting of Stella was a finalist for the Bald Archy Prize 2015 and is currently hanging at Watson Art Centre, Canberra and in Sydney. The artist’s accompany statement for this portrait states:

“I’ve been an atheist ... ever since I first heard that there was only a stairway to heaven”, said Stella Young, journalist, disability advocate and comedian. Born with osteogenesis imperfecta, Stella used a wheelchair for most of her life, which ended too soon on December 6, 2014, aged 32. Noted also for her red polka dot shoes, the artist reckons she and they winged their way up nevertheless.

“Disability doesn’t make you exceptional” but it did make Stella Young – exceptional

Stella Young died too young of an aneurism at the age of 32 on December 6, 2014. She was a passionate, provocative and funny activist for disabled people, studying to become a teacher before beginning a career in journalism and comedy, which she used to great effect.

Stella Young did not like labels, especially the inspiration one.

Stella put it best incisively, as she did on just about everything to do with disability (in edited extracts from her TEDxSydney talk filmed April 2014):

“I grew up in a very small country town in Victoria [Stawell]. I had a very normal, low-key kind of upbringing. I went to school, I hung out with my friends, I fought with my younger sisters. It was all very normal. And when I was 15, a member of my local community approached my parents and wanted to nominate me for a community achievement award. And my parents said, “Hm, that’s really nice, but there’s kind of one glaring problem with that. She hasn’t actually achieved anything.”

“But they were right, you know. I wasn’t doing anything that was out of the ordinary at all. I wasn’t doing anything that could be considered an achievement if you took disability out of the equation.”

“Years later, I was on my second teaching round in a Melbourne high school, and I was about 20 minutes into a year 11 legal studies class when this boy put up his hand and said, “Hey miss, when are you going to start doing your speech?” And I said, “What speech?” I’d been talking them about defamation law for a good 20 minutes. And he said, “You know, like, your motivational speaking. You know, when people in wheelchairs come to school, they usually say, like, inspirational stuff?”

“And that’s when it dawned on me: This kid had only ever experienced disabled people as objects of inspiration. We are not. For lots of us, disabled people are not our teachers or our doctors or our manicurists. We’re not real people. We are there to inspire. And in fact, I am sitting on this stage looking like I do in this wheelchair, and you are probably kind of expecting me to inspire you. Right?”

“Well, ladies and gentlemen, I’m afraid I’m going to disappoint you dramatically. I am not here to inspire you. I am here to tell you that we have been lied to about disability. Yeah, we’ve been sold the lie that disability is a Bad Thing, capital B, capital T. It’s a bad thing, and to live with a disability makes you exceptional. It’s not a bad thing, and it doesn’t make you exceptional.”

“In the past few years, we’ve been able to propagate this lie even further via social media. There are a lot of images out there. You might have seen the one of the little girl with no hands drawing a picture with a pencil held in her mouth. You might have seen a child running on carbon fibre prosthetic legs. These (images) are what we call inspiration porn. And I use the term porn deliberately, because they objectify one group of people for the benefit of another group of people. So in this case, we’re objectifying disabled people for the benefit of nondisabled people. The purpose of these images is to inspire you, to motivate you, so that we can look at them and think, ‘Well, however bad my life is, it could be worse. I could be that person.’”

"But what if you are that person? I've lost count of the number of times that I've been approached by strangers wanting to tell me that they think I'm brave or inspirational, and this was long before my work had any kind of public profile. They were just kind of congratulating me for managing to get up in the morning and remember my own name."

She went on ... *"and life as a disabled person is actually somewhat difficult. We do overcome some things. But the things that we're overcoming are not the things that you think they are. They are not things to do with our bodies. I use the term 'disabled people' quite deliberately, because I subscribe to what's called the social model of disability, which tells us that we are more disabled by the society that we live in than by our bodies and our diagnoses."*

"And I know what you're thinking. You know, I'm up here bagging out inspiration, and you're thinking, 'Jeez, Stella, aren't you inspired sometimes by some things?' And the thing is, I am. I learn from other disabled people all the time. I'm learning not that I am luckier than them, though. I am learning that it's a genius idea to use a pair of barbecue tongs to pick up things that you dropped. I'm learning that nifty trick where you can charge your mobile phone battery from your chair battery. Genius. We are learning from each other's strength and endurance, not against our bodies and our diagnoses, but against a world that exceptionalises and objectifies us."

"I really want to live in a world where disability is not the exception, but the norm. I want to live in a world where we don't have such low expectations of disabled people that we are congratulated for getting out of bed and remembering our own names in the morning. I want to live in a world where we value genuine achievement for disabled people, and I want to live in a world where a kid in year 11 in a Melbourne high school is not one bit surprised that his new teacher is a wheelchair user."

"Disability doesn't make you exceptional, but questioning what you think you know about it does".

As a fierce advocate for genuine achievement, Stella pointed out *"half of all people with disabilities [in Australia] live near or below the poverty line. Less than 40 per cent of us participate in the workforce ... In fact, Australia ranks last among the OECD countries when measured on quality of life for people with disabilities"*.

Stella Young on that quality of life for disabled people in Australia:

"I dance as a political statement, because disabled bodies are inherently political, but I mostly dance for all the same reasons anyone else does: because it heals my spirit and fills me with joy".

Stella Young was born with osteogenesis imperfecta, a genetic disorder that causes bones to break easily, beginning a life of advocacy at the age of 14. On her death, tributes poured in for Stella, who among many things, was the former editor of the ABC's disability news and opinion website, Ramp Up.

Federal Opposition Leader Bill Shorten described her as 'a fierce advocate for people with disabilities'. *"She has battled discrimination because of her disability. But she was a much larger than life figure and she's going to be sorely missed"*, he said.

Federal Victorian senator and Assistant Minister for Social Services Mitch Fifield said Young had a *"generosity of spirit and taught many pollies ... a great deal"*.

Former Prime Minister Julia Gillard, who introduced the National Disability Insurance Scheme: “*Stella Young was a shining light for care and action on disabilities. We mourn her passing and rededicate ourselves to her spirit*”.

Victorian Premier Daniel Andrews said she had made the state a more ‘caring and compassionate place’. “*Stella dreamt of a society where people with a disability who studied, worked and achieved great things were conventional, even ordinary*”, Mr Andrews said in a statement. “*As she leaves this world, that dream is ever closer. While Victoria is poorer for her passing, I know she has inspired a generation of Victorians, of every background and ability, to live a life without limits*”.

Stella was a passionate advocate for women experiencing family violence. She was a member of the Victorian Disability Advisory Council, the Ministerial Advisory Council for the Department of Victorian Communities, the Youth Disability Advocacy Service and Women with Disabilities Victoria.

As a comedian, she was a two-time state finalist in Melbourne International Comedy Festival’s *Raw Comedy* competition and hosted eight seasons of Australia’s first disability culture program, *No Limits*, on Channel 31. She had been a regular contributor to ABC’s *The Drum* since 2011, writing about issues for disabled people in the wider community and the disability services sector, as well as covering the 2012 Paralympics from London.

Australian Paralympic Committee Chief Executive Jason Hellwig said the disability community had lost one of its most prominent and passionate spokespeople. “*Stella was never afraid to tell it like it is, to challenge people’s perceptions and to fight for what she believed in*”, Mr Hellwig said.

The insight Stella was able to provide was a great asset to the ABC’s coverage because of her ability to look critically at the wider impact of the Paralympic Games.

“*It is not just about the athletes, the sports and winning medals, it is about so much more than that. Stella knew that better than most and that was reflected in the depth and quality of the stories she told*”.

On the NDIS, Stella Young told Jon Faine’s ABC radio program:

“*I’m very annoying like that, I’m like a mosquito, just constantly buzzing, small but persistent*”, she said. She hoped the scheme would become more like the United Kingdom’s *Disability Living Allowance*.

“*It’s a recognition that it costs more to be a disabled person*”, she said.

“*Those kind of things are factors that affect me in small and large ways – things like having to get taxis because some forms of public transport aren’t accessible, having to alter all my clothes because nothing fits me. I hope that we can move to a system where those extra costs, no matter how big or small, are met.*”

Support Group Changes

The Hills District Support Group convenor, Moya Adams, advises us that they have recently changed their meeting date to the **2nd TUESDAY** of each month at 10:30 am, West Pennant Hills Sports Club.

The Sutherland Support Group convenor, Ruth Hatton, reminds us that they now meet at the **TRADIES CLUB**, Gymea on the 1st Wednesday of each month at 2:00 pm.

Polio Post



Susan Stewart has a request of our members. Susan has been a member of Polio NSW since the early days, and at one stage was Convenor of the Grafton Support Group. She has since moved back to Sydney. Hopefully there are some of our members who can also provide some stories/photos to Liz Macqueen. Susan's "Collaroy Story" is included in this newsletter.

Subject: Collaroy Convalescent Home Archive

I am writing to you in the hope of contacting any of our members who were patients in the Collaroy Convalescent Home, which was part of The Royal Alexandria Hospital for Children at Camperdown. I was at Collaroy for several months in 1954.

I recently met Liz Macqueen, who is a Foundation Director of the Sargood Foundation which is a non-profit organisation rebuilding the former Collaroy Convalescent Home into a Rehabilitation Residential Centre for people living with a Spinal Cord Injury. Their website (www.sargood.org.au) shows details and photos of the rebuilding project.

She is interested to hear from anyone who has had any association with the former Convalescent Home, as they are trying to establish an archive of the years when it was part of the Children's Hospital.

I was eleven/twelve during my stay there, but only have one small Box Brownie photo, and vague memories of staff and other patients. Perhaps someone can help! I would be happy to hear any stories I can pass on, and am delighted that this wonderful spot will continue to be used for such essential rehabilitation.

With best wishes, Susan Stewart

From: Liz Macqueen <liz@macment.net>

Subject: Sargood at Collaroy

Hi Susan

It was nice to meet you the other day at Wakehurst. Following on from our conversation regarding the new development at Collaroy and your history I would very much like to get a couple of things from you. As I mentioned, when the centre is open early next year we hope to have a book at reception detailing the history and journey of the site.

What we would like if you have time:

1. any photos you may have of yourself/the Hospital as it was including other patients/staff etc. (with brief explanation of what each is)
2. any stories you have of yourself, your memories of your stay and what you saw around you/other patients staff etc. Good stories/funny stories anything at all that you or your sister remembers.

Susan, I know this may take you some time however, anything you have to offer would be fantastic to help us with our story.

If at any time you are down this way by all means pop into our (very small temporary) office on the site and Sam will show you around – including showing you some of the stories and photos we have to date. You can also google us on <www.sargood.org.au>.

Thanks once again for offering this and I really look forward to receiving anything you wish to send us.

Kind regards

Liz Macqueen, Director

Sargood Foundation
1 Brissenden Avenue
Collaroy NSW 2097



2015 Polio NSW Seminar Program

Saturday 5th December

Burwood RSL Club
96 Shaftesbury Road
Burwood

Annual General Meeting and Seminar

Look out for the Seminar details in the next issue of Network News

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

The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. There are currently more than 2,000 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>. 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.



**2016 Australasia-Pacific
Post-Polio Conference
Polio - Life Stage Matters**

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