

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/wmwwesternsyd2015) 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:

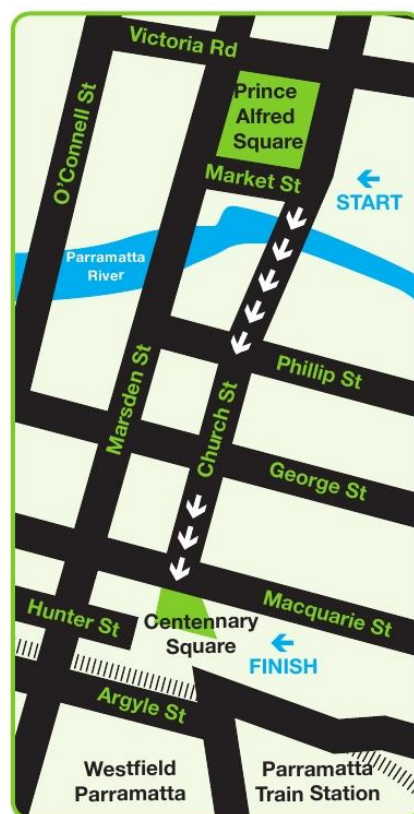
Wednesday 16 September, 2015

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



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/wmwwesternsyd2015>.

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 Queens 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



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 favourably, 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 polities ... 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**, Gympie on the 1st Wednesday of each month at 2:00 pm.



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 <i>Look out for the Seminar details in the next issue of Network News</i>
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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

**20-22
SEPT
2016**

**FOUR
SEASONS
HOTEL
SYDNEY**

**SAVE
THE
DATE**



Volume 5, Issue 2

Polio Oz News

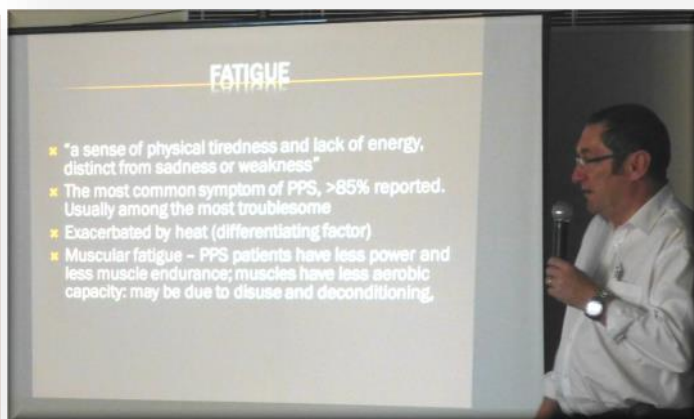
June 2015—Winter Edition

2015 Victorian Polio Health and Wellness Retreat

Dear Mary-ann, just a further note of heartfelt thanks for all your hard work putting together such a well organised and inspiring Retreat.

I have been guilty in the past of refusing to admit to very few, including myself at times, to the fact that I am a polio survivor. After such a life changing few days in the company of so many amazing other survivors, I now acknowledge the term as a badge of honour.

Thank you, thank you, thank you—from a very appreciative participant. FL



Dr Stephen de Graaff's Plenary session "The Polio Body"

TORQUAY 2015 POLIO RETREAT

By Ron Blackwell (South Australia)

Putting aside what we all went for, what a magnificent venue. Initially a bewildering array of lifts, stairs and passage ways gave way to lovely views of the southern ocean in what proved to be brilliant weather.

The organisers are to be commended for such outstanding quarters and the location. In true polio survivor tradition everyone was pretty good on the tooth, putting away a breakfast that would satisfy a shearer and checking in at every morning and afternoon tea.

The Program

Having attended the retreat at Glenelg, I wondered what the theme of Mind, Body and Spirit could offer. A check of the Program showed that it followed the same theme with similar topics but the presenters and their approaches were refreshingly different and very informative.

Peter Willcocks from the Bayside Polio group spoke to and presented a short film "[All Walks of Life](#)" at the Thursday evening meal. A simple interview theme, the film was clear and informative as people spoke of their polio experiences.



Cont'd p4

National Patron: Dr John Tierney, Ph.D, DAm

Polio Australia

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throughout Australia

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Inside this issue:

Health & Wellness Retreat	1
Supporting Polio Australia	8
Donate to Make a Difference	9
Fashion, Fiesta and Tapas!	10
Shine the Light Report	11
Mobility Insurance	11
Jo's ANZAC Inspiration	12
PPS as a Viral Disease	13
Treatment for PPS-Cochrane	14
PPS Research Funding	15
Yoga for Post-Polio	15
Universal Design Website	15
Pramipexole and PPS	16
CHF on the 2015-16 Budget	16
COTA's Budget Response	17
Productive Ageing Report	17
Slowing Cognitive Decline	18
High Morale=Longer Survival	18
Vaccines for Older Adults	20
Misc Health Studies	22
Polio This Week	25

From the President



Dr John Tierney
President

Everyone who attended this year's sixth annual Health and Wellness Retreat in Torquay, Victoria, acclaimed it as the best ever.

Although I have been to all of them, I really learnt a lot this time, thanks to the variety of topics and the quality of the invited speakers. Mary-ann, as usual, did an excellent job in putting this together and managing the day-to-day program. This will be the last Retreat for two years as next year's big event for learning about the Late Effects of Polio (LEoP) will be at the Australasia-Pacific Post-Polio Conference in Sydney. So if you missed Torquay this year, please join us in Sydney from 20-22 September 2016.

It was really great to have our friends across the ditch join our Retreat when Polio New Zealand President, Barry Holland, and Treasurer, Diane Mathews, took part in the Torquay Retreat. As we were on the international stage, I am very glad that it was our best Retreat ever. In August Polio NZ are putting on their own Health and Wellness Retreat in Hamilton, NZ, and to further strengthen the growing bonds between our two national organisations, Mary-ann and I will be taking part. I have been invited to be the guest speaker at the Polio NZ Retreat dinner and I am sure that Mary-ann will say something.

During the Retreat, I made a call

for more speakers for our "We're Still Here!" program of talks at Rotary clubs. Sue Mackenzie and I have now spoken to dozens of clubs and this has now become a significant part of our fund raising for Polio Australia. However, we need more speakers. I was heartened by the response to my call at the Retreat for speakers and we now have a panel of twenty-one polio survivors who have agreed to arrange to speak to Rotary Clubs in their area. If you would like to join our panel of speakers, and receive our speaker's package please contact [Mary-ann](#).

Over the last eighteen months we have continued to build strong links with Rotary. I am currently changing my focus here to now work more at the District level of Rotary International. In March, I conducted a LEoP stall over two days at the Rotary District 9685 (covering the northern half of Sydney and the central Coast) Annual Conference in the Hunter Valley to promote, in particular, Rotary's involvement in our international Conference next year. After that, something really wonderful happened. Rotary District 9685 is now liaising with Polio Australia to set up a program of clinical workshops to provide instruction and resources for health care professionals. Following the successful pilot program in Victoria in 2014, Polio Australia was encouraged to explore ways of facilitating further professional development workshops for a range of allied health professionals who work with post-polio patients. A Past District Governor of District 9685, and his team, are now preparing to 'sell' and prove the concept to District 9685 Leaders before moving forward to promote a

Cont'd p3

From the Editor



Mary-ann Liethof
Editor

Like most 'southerners', winter in Melbourne makes me long for a trip north to sunny Queensland! If you are lucky enough to be in Brisbane this August, you may well be interested in a fabulous and fun Sunday afternoon of 'Fashion, Fiesta, and Tapas' being put together by the irrepressible Sue Mackenzie

and friends! This is a fundraising event for Polio Australia—all details on [page 10](#).

Throughout this edition there are a number of articles provided by participants who attended the 2015 Retreat in Torquay. I am very pleased to see that they got so much from the weekend. Of course, there is always a lot of work involved, but we benefit greatly from a broad range of fantastic session presenters wherever we go, most of whom offer their services pro-bono. And this was no different, so a big "THANK YOU" to everyone who participated!

(Sigh!) It is that time of year when all charities seem to be pitching for 'end of financial year' donations. I have received numerous emails, letters, and phone calls myself, and I'm sure I'm not the only one! However, as Polio Australia is also a 'charity', we need to jump on the bandwagon. So if you have any spare change, [page 9](#) provides details as to how you can donate to the work of Polio Australia. Every bit helps—really!

On [page 12](#), you can read about an inspiring ANZAC mural which was painted by polio

survivor, Jo Gordon, from South Australia. There are just so many talented people out there!

The May 2015-16 Budget sparked a number of policy statements of relevance to many readers, with two being of particular interest from the Consumers Health Forum (CHF) and Council on the Ageing (COTA). See how you fare on [pages 16 and 17](#).

As always, I have also collected a number of what I think of as being interesting studies relating to health and ageing issues. For instance, did you know that we may soon have a vaccine for pneumonia? And have you had your 'flu shot yet? If you live in Australia, it's definitely the season for it. These articles can be explored further on [pages 20 and 21](#).

We will all be relieved to see that polio infections in Pakistan have fallen by 70% this year. It is great to see the polio eradication efforts making inroads. [Pages 24 and 25](#) have all the details.

As of this week, the official [Australasia-Pacific Post-Polio Conference website](#) is now up and running. We already have 13 International and 11 Australian Keynote Speakers and/or clinical workshop facilitators. A 'Call for Abstracts' is currently out for presentations based on "Life Stage" themes, which may include: Rehabilitation, Clinical Practice, Clinic Models, Self-Management Strategies, Psychology, Research, Assistive Technology, Universal Design, Immunisation, and Needs in Developing Countries. **Please help us spread the word!** 🌐

Mary-ann

From the President (cont'd)

similar series of seminars in ALL Rotary Districts around Australia. The next step will be a meeting between the executives of Polio Australia and the District 9685 executive to further discuss and develop all aspects leading to a final agreement.

Planning for Polio Australia's *Australia-Pacific Post-Polio Conference* in Sydney (20-22 September 2016) is now well advanced with all the necessary infrastructure now being put into place. Gillian Thomas has done excellent work on putting the necessary websites in place. Mary-ann continues to work miracles with the growing levels of international involvement in our 2016 Conference, with both Joan Headley, Director of Post-Polio Health International (USA), and John

McFarlane, President of the European Polio Union, being part of the Steering Committee. They are taking part in our Conference calls and lending their expertise as organisers of past international Conferences. We also welcome Gordon Jackman to the Steering Committee, who is representing the Board of Polio New Zealand. Although we expect this Conference to attract a large number of health professionals, we would also like to see as many polio survivors attend as possible, so please pencil the 20-22 September, 2016 into your diaries and keep an eye out for developments in forthcoming months at www.postpolioconference.org.au. 🌐

John

Polio Health and Wellness Retreat (cont'd)

The real work began at 9.15 Friday morning with Dr Stephen de Graaff giving the open plenary session on the Challenges in Post-Polio. I, along with a few others, attended with wives and partners which meant going to different sessions throughout the Retreat. So while I attended Pain and Fatigue Management, Ray was attending Exercise Options, and so it continued for three days, which gave us a wider cover of the Program. Some sections had a repeat session, but with four programmes running in each 1½ hour period there were still some that were missed.

Saturday's theme centred on a Healthy Mind, which included topics such as Mindful Self Compassion, Creative Writing, Cryptic Crosswords, plus 11 other topics.

Saturday night was topped by a very accomplished concert. What talent! Especially as the choir was established in 1½ hours by an expert musical director, Shaun Islip, who also led a session called "Find Your Voice".

I chose to do the voice session, but I could have chosen Kazdoodling, Ikebana or Family History.

Sunday's Program "The Healthy Spirit" featured Worship Through Music, Meditation, or Philosophy.

It was a privilege to attend and become reacquainted with those I had met at Glenelg. I also made contact with fellow South Australians, Bill and Helen Stock from Lucindale, Lyn Lillecrapp from Gawler, and the three sisters Elizabeth Doecke, Charmaine Griswood and Yvette Reade.

A wonderful, inspiring weekend!

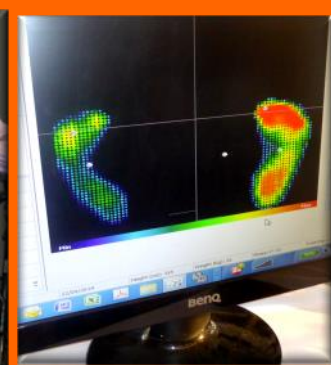
Ed Note: Retreat details, including handouts, can be found online [here](#).



Exercise Options



To Brace or Not To Brace



Maintaining Mobility



Being Medicine-Wise

Polio Health and Wellness Retreat (cont'd)



Auction, Raffle, Donations and Sales



Polio Australia was delighted to have available to auction six exquisite paper tole pictures donated by Bill Peacock (Queensland); an extraordinary chess set (*pictured left*) and table from Joan and Graeme Smith (Victoria); together with a wonderful warm knee rug crocheted by Fay Powell (New South Wales) for the raffle prize.

Fiona Waters did a great job at auctioneering, raising \$1,345 for the pictures and chess table.

Retreat participants were clearly feeling very generous during the Retreat weekend, with more than \$1,500 in total being banked from the auction, raffle, donations, and the sale of [clinical practice resource](#) books.

Polio Australia sincerely thanks everyone who participated for making such a great effort!—Ed 🌈

Polio Health and Wellness Retreat (cont'd)

Source: EASTERN NEWS

—MAY 2015 Edition

(Newsletter of Eastern Polio Support Group Inc.)

Reprinted with kind permission of the authors

Wellness Retreat, 2015 Wyndham Resort Torquay 30 April-3 May. The maximum of 70 people attended the Retreat coming from Queensland, New South Wales, Tasmania, Victoria and two from New Zealand who will be running their first Retreat later this year. For some people it was their sixth retreat but many were attending for the first time. Carol and John Membrey, Fran Willmott, Janice Gordon, Robyn Abrahams and Margaret Walker were the six members who attended from Eastern Polio Support Group and it was the first retreat for most of us. Here is what some of our attendees had to say:

My first Polio Retreat proved to be all that I had expected and more. Mary-ann Liethof put together an incredible program with plenty of scope for individual choice. If only I could have been in two places at once! A highlight for me was to meet a few other South Australians who contracted polio at a similar time to me. We talked of Northfield Infectious Diseases Hospital and Somerton Children's Home in SA. It was also good to spend time with those from our own group. New experiences included introduction to cryptic crosswords and 'Kazdoodling'. I'm still going through the various handouts we received and learning from them.

Carol Membrey



Members of the Eastern Polio Support Group

Besides benefitting from the great program, good accommodation, brilliant organisation and the chance to talk to a number of new people, I was inspired by the acceptance of, and coping with, problems of those suffering from the late effects of polio. The humour shown throughout the retreat by everyone was contagious. I learnt a great deal from these people by understanding more deeply their varied conditions, and also so much more about the problems associated with the limited knowledge so many doctors have of this condition. I will always remember the good will and companionship which was shown throughout the retreat.

John Membrey

For me it was a time to learn, share with others and relax. No thinking about meals apart from turning up at the allocated time. Free to rest, exercise or participate as I wanted . . . what bliss. The weekend was billed as benefiting Body, Mind and Spirit. Well my body certainly enjoyed the swim in the indoor pool and in time should benefit from Stephen de Graaff's emphasis on 'pacing

yourself'. I will also put into practice Anne Duncan's advice regarding breathing. Andrew Sinclair's comments on how important effective decision making is really hit home. I had never met the term *Mindful Self Compassion* before and from the expert it did make sense. Care for your Mind and the body will thank you. What most lifted my Spirit would have to be singing under the leadership of Shaun Islip—great fun. The trip there and back was never dull with 2 others in the car. A great time to share.

Fran Willmott

I thoroughly enjoyed our time at the Torquay Retreat. All sessions I attended were interesting and informative. Something a bit different was the session I attended on 'Kazdoodling'. We started the session watching a video of people doodling, then completed a part finished origami bird—very hard. We traced around the top of a box, using a black pen filled this in with doodles, just the same as doodling when waiting on the phone, etc. I started with a bird, which I filled in doodling and then doodled the surrounds. Some of the finished

Polio Health and Wellness Retreat (cont'd)

articles were fantastic—a lot of artistic people out there. The men had a go and were very funny with their comments. We then cut this out and pasted it onto the top of the box and decorated it with ribbon, cut outs, words and other pieces, which were provided. I loved this session—it was interesting, relaxing and fun. Another different session was run by Mary-ann Liethof titled "What's Your Type?". Lots of laughter and loads of differing opinions on what our 'Types' were.

[Using the Myers-Briggs Type Indicator.] I also enjoyed the movie/doco "Afternoon of a Faun". This was about a ballerina, Tanaquil Le Clercq, who, whilst on a tour of Europe, contacted polio and never danced again.

Janice Gordon

From the moment we booked in at reception we could tell that this was going to be a very special Retreat and it did not disappoint. Wyndham Resort is situated on Zeally Beach,

Torquay, and the ocean views were superb and the days fine and sunny. Mary-ann Liethof worked tirelessly throughout the 4 days and the program provided answers for many people. I gained much from the workshops I attended and have a better understanding of when to rest, what to expect and where to go for help. The genuine feeling of friendship and understanding of other people's difficulties was very powerful.

Margaret Walker

RETREAT! THE CRY RANG OUT ACROSS THE LAND

By Denise Stanford (pictured far right)—**Geelong Polio Support Group**



So we, usually the minority, became the majority. Refreshing to find that here we mingled with others who know Polio, either from direct experience or from association. A few days with a complete body of believers where we did not have to explain ourselves. How amazing!

The Wyndham Resort in Torquay, Victoria, hosted the retreat, providing good food, accommodation and much TLC.

Here we would regroup, to rekindle the fire that keeps us going.

I've always thought of a retreat as relaxing but this was a Polio Australia Retreat so offered the opportunity to be busy, busy, busy, along with the understanding that we pace ourselves, resting when needed. The vast array of activities stirred Body, Mind, and Spirit, to encourage us to open further to new experiences and possibilities or reawaken the dormant.

Personally I sang with an impromptu choir, was stirred to write again and experienced my first relaxation massage (the pain easing benefits of which still remain). Others experienced walking with Nordic Poles, Doodling and Ikebana. They wrestled with the Cryptic, Philosophical and many other things. To think I almost didn't go, being very grateful for my last minute inclusion; but I regret not one moment.

Yes it can be confronting to consider what may be ahead, but the determination of the Polio Survivor is contagious, it could be felt so strongly. It was reflected in the ocean waves intent on repeatedly gaining the sandy shores of the beautiful Victorian coastline visible from the resort windows. I know some of the young staff serving us had never heard of Polio—they know now!

Polio survivors will not be defeated, but we do retreat, to fight another day!

If you missed it, start saving now and make your mind up to be part of the next Polio Australia Retreat hopefully to be held in 2017. 🌈

A Donation to Polio Australia Will Make a Difference!

As the end of the financial year approaches, Polio Australia is urging you to consider a charitable donation that could assist your tax return while supporting important and exclusive work on behalf of Australia's polio survivors.

Although Polio Australia is the peak national body representing Australia's polio survivors, we receive no government or any other regular funding, so every donation helps – small or large! 100% of all donations to Polio Australia will go towards the goal of ensuring that polio survivors in Australia have access to appropriate health care and the support required to maintain independence and make informed life choices.

Polio Australia is endorsed by the Australian Taxation Office as a Health Promotion Charity and a Deductible Gift Recipient making all Australian donations over \$2 tax deductible. An official receipt will be provided for all donations received.

Your donation will go directly towards activities including:

- supporting the annual Polio Health and Wellness Retreats, which provide education and life-changing strategies for polio survivors and their families, and engage local health professionals
- developing clinical practice resources to inform health professionals about the Late Effects of Polio
- running clinical training workshops for allied health professionals
- resourcing projects like the 2016 Australasia-Pacific Post-Polio Conference

- producing the quarterly e-magazine "Polio Oz News"
- maintaining the Australian Polio Register and other vital web-based information
- ongoing government lobbying and advocating for appropriate services for polio survivors
- the October Polio Awareness Month "We're Still Here!" campaign, and other public engagements to raise awareness of the issues faced by the post-polio community

Your Donation can be made via any of the following methods:

View online:

www.polioaustralia.org.au/invest-in-us/

Cheque

Please make cheques out to **Polio Australia Inc** and post to PO Box 500, Kew East, Vic, 3102

Electronic Funds Transfer

Bank: **Westpac**

Branch: **Parramatta, NSW**

BSB: **032-078**

Account Number: **555766**

Account Name: **Polio Australia Incorporated**

Credit Card or PayPal

Your credit card donation is securely processed through PayPal on behalf of Polio Australia. You do not need to have your own PayPal account. Simply click the Donate button below to begin.



Thank you for helping us to make a difference in the lives of people living with the Late Effects of Polio.



"We're Still Here!" Campaign—Parliament House Canberra

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SUNDAY 9TH AUGUST 2015

2:30pm for 3:00pm

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More information—sgmackenzie@bigpond.com

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Shine the Light

Report on Rotary District 9600 Conference—Hosted by the Rotary Club of Bribie Island on 1-3 May 2015

By William (Bill) Peacock
OAM—Guest Speaker (pictured)

The theme of the Conference was "*Shine the Light*" and, as Guest Speaker, I used this theme to highlight the need for shining the light on Polio Australia representing polio survivors throughout Australia.

The show of hands when I asked how many people in the room (300) knew about the Late Effects of Polio/Post Polio Syndrome resulted in about 30 hands up—and they belonged to members of the Rotary Clubs I had already spoken to. During Question Time a number of people talked about relatives who had polio and asked who should they speak with. I spoke about the Australian Polio Register and referred to the web page and the great work of Polio Australia.



I then introduced the delegates to the "*Polio Health and Wellness Retreats*" stating that one was taking place as we spoke. I was able to use three photos from Facebook from the Retreat, which was of great interest.

The Conference was impeded by a severe weather incidence with torrential rain and flooding—five people in Caboolture lost their

lives in flood waters. The roads on and off Bribie Island and the Bruce Highway travelling North and South were closed Friday afternoon. Many homes and businesses were inundated, triggering a major disaster notification from the Queensland Government. The situation also impacted on the arrival of many Conference delegates on the Island.

Of course, I was well aware of the natural disaster taking place, and understood the inability to make an instant financial commitment with so many organisations being called on to support the flood-related problems facing so many in our community. However, I have no doubt that there will be a financial commitment at some stage, and I will continue to keep in touch with the Rotary Clubs in the Region. 🌊

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Jo's ANZAC Inspiration

The Weekender Herald - April 24, 2015 - page 7

ANZAC mural a labour of love for Jo

by Hayley Waller

The Littlehampton Community Association will be holding their annual ANZAC Day Dawn Service in Miels Park, Littlehampton.

To commemorate the centenary of the Gallipoli landing, two documentaries will be shown prior to the dawn service.

Gallipoli: The First Day and Boys of the Dardanelles will screen from 5.45am with the service beginning at 6.30am.

A 'gunfire' breakfast will follow the service with the significance of the name coming from the ANZAC tradition of soldiers pouring rum into their morning tea to work up the courage to fight for another day.

Secretary of the Littlehampton Community Association Karen Liebelt said that there will also be a display of memorabilia in the community hall.

"It is important for us to remember the sacrifice of those who served made for what we have today," Karen said.

This year's dawn service will also be celebrated by the unveiling of a mural depicting the story of the Anzacs in Egypt and their landing at Gallipoli.

The Littlehampton Community Association commissioned local artist Jo Gordon to complete the banner that spans the hall's inner wall.

At the age of 70 Jo has been dealing with post-polio syndrome for the past decade, and completing this mural, although challenging for her, has been a real labour of love.

Jo has worked on the piece for over three months with over 300 hours of painting time. She has also had some special helpers.

Jo's granddaughters, Anna and Mia, have been helping Jo these school holidays by putting on some



Anna Jacobs (8), Jo Gordon and Mia Jacobs (10)

of the finishing touches to the mural's soldiers.

"It has been lovely to see the girls help me and really appreciate the time I have put into the piece. It is a really radiant feeling," Jo said.

"Both of the girls have now gone back to drawing."

Jo said that completing the piece over the past few months has been quite an emotional journey.

"I have watched the DVD distributed by the Department of Veteran's Affairs, 342 Days at Gallipoli, seven times while painting the mural," Jo said.

"I have also been reading Gallipoli Diaries by Jonathan King during my breaks to get a feeling of what they went through and reflect on their sacrifices."

The mural will be revealed in its complete form on Saturday and

the Anzac Day Dawn Service at Littlehampton, but will travel to other places in the region.

Jo has been honoured to complete the piece and says she has no signs of slowing down, confident that she will continue to paint.

She hopes that the local community will be as impressed by the banner as much as her family and friends have.

"I hope that it touches the lives of not just the older generations but younger people too.

"I hope they understand that we don't need wars, but to get a feeling of togetherness and understand the teamwork shown during the wars.

"I hope the mural can encourage team spirit and for people to care for one another."

The dawn service will be held at Miels Park followed by a community breakfast in Peace Memorial Hall.

Jo's ANZAC Inspiration (cont'd)



Jo Gordon's ANZAC Mural

Post-Poliomyelitis Syndrome as a Possible Viral Disease

Earlier this year, Polio Australia, along with the [European Polio Union](#), and [Post-Polio Health International](#), were contacted by [Dr Antonio Toniolo](#), Professor and Director of the University Department of Clinical and Biological Sciences, University of Insubria, Varese, Italy, requesting 'local' information to inform a paper he and Dr Baj Andreina were preparing for the [International Journal of Infectious Diseases](#). This was published online on the 26th of May 2015.—Ed

Summary

This review summarizes current concepts on post-polio syndrome (PPS), a condition that may arise in polio survivors after partial or complete functional recovery followed by a prolonged interval of stable

neurological function. PPS affects 15–20 million people worldwide. Epidemiological data are reported, together with the pathogenic pathways that possibly lead to the progressive degeneration and loss of neuromuscular motor units. As a consequence of PPS, polio survivors experience new weakness, generalized fatigue, atrophy of previously unaffected muscles, and a physical decline that may culminate in the loss of independent life. Emphasis is given to the possible pathogenic role of persistent poliovirus infection and chronic inflammation. These factors could contribute to the neurological and physical decline in polio survivors. A perspective is then given on novel anti-poliovirus compounds and monoclonal antibodies that

have been developed to contribute to the final phases of polio eradication. These agents could also be useful for the treatment or prevention of PPS. Some of these compounds/antibodies are in early clinical development. Finally, current clinical trials for PPS are reported. In this area, the intravenous infusion of normal human immunoglobulins appears both feasible and promising.

The full article can be downloaded [here](#).

Ed Note: Dr Toniolo will be a Guest Presenter at the [2016 Australasia-Pacific Post-Polio Conference](#) in Sydney next year.



**2016 Australasia-Pacific
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Treatment for Post-Polio Syndrome



Source: www.cochrane.org—Published 18 May 2015

Authors: *Koopman F, Beelen A, Gilhus N, de Visser M, Nollet F*

Review question

What are the effects of different treatments in people with postpolio syndrome (PPS)?

Background

PPS is a condition that can affect polio survivors years after recovery from an initial paralytic attack by the polio virus. PPS is characterised by progressive or new muscle weakness or decreased muscle endurance in muscles that were previously affected by the polio infection and in muscles that were seemingly unaffected. Other symptoms may include generalised fatigue and pain. These symptoms often lead to a decline in physical functioning, for example, trouble walking. The objective of this review was to assess the benefits and harms of different drugs and rehabilitation treatments compared to placebo (a pill or procedure without any physiological effect), usual care or no treatment.

Study characteristics

We searched scientific databases to find all studies on treatments for PPS up to July 2014. We found 13 studies involving a total of 675 participants that were of sufficient quality to include in this review. Ten studies evaluated the effects of drugs (modafinil, intravenous immunoglobulin (IVIg), pyridostigmine, lamotrigine, amantadine, prednisone), and three studies evaluated other treatments (muscle strengthening, rehabilitation in a warm climate (that is temperature $\pm 25^{\circ}\text{C}$, dry and sunny) and a cold climate (that is temperature $\pm 0^{\circ}\text{C}$, rainy or snowy), static magnetic fields).

Key results and quality of the evidence

IVIg is a treatment in which antibodies that have been purified from donated blood are given as an infusion into a vein over a period of time. There was moderate- and low-quality evidence that

IVIg has no beneficial effect on activity limitations in the short term and long term, respectively. Evidence for effectiveness on muscle strength was inconsistent, as results differed across studies. IVIg caused minor side effects in a substantial proportion of the participants.

Lamotrigine is a drug used to help control certain kinds of epilepsy and to treat bipolar psychiatric disorder. Results of one trial provided very low-quality evidence that lamotrigine might be effective in reducing pain and fatigue, resulting in fewer activity limitations, and in this study it was well-tolerated. We based these conclusions on results of only one small trial with important limitations in study design.

There was very low-quality evidence that muscle strengthening of thumb muscles is safe and beneficial for improving muscle strength. Again, we based these conclusions on results of only one small trial with important limitations in study design, and they are applicable only to thumb muscles.

Static magnetic fields is a therapy in which electrical currents are applied to the skin with the intention of reducing pain. There was moderate-quality evidence that static magnetic fields are safe and beneficial for reducing pain directly after treatment, although functional effects on activity limitations and long-term effects are unknown.

Finally, there was evidence varying from very low quality to high quality that modafinil, pyridostigmine, amantadine, prednisone and rehabilitation in a warm or cold climate are not beneficial in PPS.

Authors' conclusions:

Due to insufficient good-quality data and lack of randomised studies, it was impossible to draw definite conclusions about the effectiveness of interventions for PPS. Results indicated that IVIg, lamotrigine, muscle strengthening exercises and static magnetic fields may be beneficial but need further investigation to clarify whether any real and meaningful effect exists.

[Read the full abstract.](#)

Post-Polio Research Funding

The Research Fund of Post-Polio Health International (PHI) is looking for researchers interested in studying post-poliomyelitis or neuromuscular respiratory insufficiency.

The call for funds to be dispensed in 2016 is broad. The Research Committee is asking for proposals to study the cause(s), treatment and management of the late effects of polio or neuromuscular respiratory insufficiency or to explore historical, social, psychological and independent living aspects of living with polio or with long-term mechanical ventilation.

The research must have the potential to improve the lives of polio survivors or ventilator users. Preference will be given to innovative or original research, which leads to new interventions, products, methods or applications.

The maximum amount of the award for one year is US\$50,000. PHI will accept proposals that require two years to complete for a maximum of \$100,000.

The 'Request for Proposals Guidelines' can be downloaded from PHI's homepage, www.post-polio.org, or from the 'Research' tab. The 'Applicant Information', required when submitting a proposal, is also available for download.

October 1, 2015 is the deadline. The Research Committee will review the proposals and make its recommendation to the PHI Board of Directors, who will make the final decision in December 2015. The funds will be distributed in 2016 or 2016/17.

PHI has funded 9 studies since 2001. ●

Yoga for Post-Polio Patients

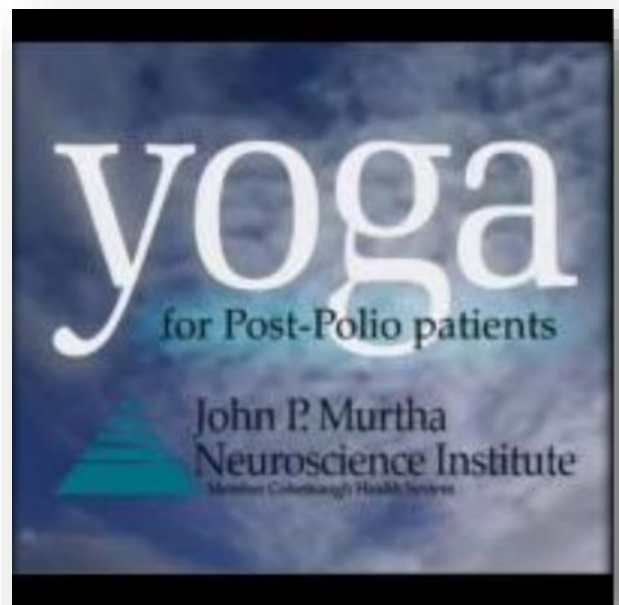
Post-Polio Health International has a number of excellent resources on their Polio Place website, including this online seated yoga video. Click on the picture (right) to link to the video.—Ed

"Our goal in this video is to introduce Hatha yoga, breath awareness and stress reduction to people with Post-Polio Syndrome in order to increase their energy, reduce fatigue and create an increased sense of well-being.

These exercises and postures can be modified according to one's abilities and limitations and can be utilized and integrated with most other medical treatment plans that a patient may be following". ●

David Riley, MD

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New Universal Design Australia Website

The aim of universalising design is to create a more inclusive world. Universal Design, as an endeavour in its own right, is being used internationally as a vehicle for bringing about wholesale change in design thinking throughout the design process so that all people are considered regardless of age, capability, or background.

Universal design is a design concept not a design product. The principles of universal design can be applied to concrete things like products, buildings and open spaces, to intellectual activities such as designing learning programs, and to conceptual things such as policies and practices. View [here](#). ●

Effects of Pramipexole on PPS Symptoms

By David McDonald (Queensland)

Following my paralytic polio and full recovery in 1952 at age 10, Post-Polio Syndrome began in the mid-90s and escalated in stages thereafter. My worst symptom was increasing central fatigue, which is incapacitating and restricting and is managed by pacing and conditioning. Over time, my nightly sleep grew from 8 hours to 9-10 hours.

In 2009, using information from the PPS literature, I started taking 3g daily of the Omega 3 fatty acids EPA/DHA (from fish oil) in order to reduce inflammation underlying the central fatigue, and this lessened the fatigue's physical and mental effects.

In 2010, I was diagnosed with Parkinson's Disease which has since progressed very slowly. Parkinson's medication began with low-dose Sinemet in 2010, followed by low-dose Sifrol ([pramipexole](#)) in 2013 at 0.75mg/day. They have helped control my PD symptoms (mainly tremors).

The effects of the pramipexole on my PPS symptoms were a big surprise. The frequency and severity of my central fatigue episodes were

significantly reduced, stamina was increased and my nightly sleep requirement dropped to around 6 hours. Pramipexole is a dopamine agonist that directly activates dopamine receptors in the basal ganglia and my Neurologist can't explain why it has affected my PPS symptoms like this.

While pramipexole's mitigation of my central fatigue is very welcome, PPS still controls my daily life.

Ed Note: According to Post-Polio Health International (PHI) there are few published comparative studies of the dopamine agonists. A study in which pramipexole compared favourably with bromocriptine did not have enough power to show a statistical difference. Read an Abstract on PubMed [here](#).

PHI advised that Richard Bruno et al had an article published in the *American Journal of Physical Medicine & Rehabilitation* about the effects of bromocriptine on PPS fatigue in 1996, which can be found online [here](#). To PHI's knowledge, the bromocriptine study was not pursued or duplicated. More about bromocriptine can be viewed [here](#). 🌟

CHF's Analysis of the Federal Health Budget 2015-16

Source: [Consumers Health Forum of Australia](#)
Email—13th May 2015

While we believe this budget is a more forward looking document than last year's, it still fails to address measures of long term concern.

We are disappointed that many of the harshest measures in last year's horror health budget remain, given the rise in chronic illness, the ageing of the population and the gaping holes in health funding over four years left from last year's cuts such as:

- The \$1.95 billion reduction in hospital funding
- The \$1.67 billion freeze in Medicare payments to doctors
- The \$435 million cut from dental funding
- The \$121 million "rationalisation" in indigenous health programs

Many patients are likely to face higher medical bills as the freeze on Medicare payments would by 2017-18 reduce the real value of the Medicare

benefit for a GP consultation by an estimated \$8.43.

Additionally, the budget contains a measure to tighten the safety net for medicine subsidies which revives fears the Government is still hoping to introduce an increase of up to \$5 in the PBS co-payment. This rise in the safety net threshold would mean patients would have to ultimately pay for eight extra prescriptions before qualifying for free or cheaper medicines.

There is further detail in the Budget papers that require appraisal before CHF takes a view on these aspects. We are preparing a more detailed analysis based on further briefings and consultations we undertake this week which we will circulate to members in the week commencing 18 May 2015.

In the meantime, we have summarised our initial impressions of the budget in a presentation, which you can access [here](#). 🌟

COTA Australia Response to Federal Budget 2015

Source: [COTA Australia](#) Policy Alert No 13—May 2015

In last year's federal Budget the most vulnerable older Australians, including pensioners, were asked to accept a disproportionate share of the burden of the government's 'budget repair' agenda.

The measures to achieve this were harsh and largely unacceptable to the Australian public. In this year's Budget the government has shifted gear to some degree, especially backing away from last year's most damaging Age Pension measures.

In this budget older Australians have fared well in regard to aged care, but less well on income security, with the government continuing its focus on cutting spending on the Age Pension. There are some gains for older people in the health budget, but overall funding



pressure continues in this area.

COTA is particularly disappointed that so soon after an Intergenerational Report that emphasised the pressures of a longer-lived and ageing society, there is no attempt in the Budget to create a new vision and narrative around ageing, or to develop new measures for good health, participation and well-being for older Australians. It is, at the end of the day, a budget which addresses older people largely in terms of aged care and pensions.

It is also a great disappointment that the government did not choose to announce a comprehensive, independent Retirement Incomes Review in this Budget and that there have since been mixed signals from government about holding such a review.

COTA has been calling for a Retirement Incomes Review since April last year, and there is now widespread support for it across the retirement incomes sector, business sector, and political spectrum.

Read the full Policy Alert [here](#).

Productive Ageing Centre Report: Appreciating Value



Source: [National Seniors](#) Email—7 May 2015

The National Seniors Productive Ageing Centre is pleased to release a new report *Appreciating value: Measuring the economic and social contributions of mature age Australians*.

This report measures the economic and social contributions that mature age Australians make to the economic sustainability of Australia. The economic contribution is measured as the net annual benefit to employers due to the lower labour mobility of mature age workers; this is

estimated to be \$27.4 billion per annum. The social contributions comprise both informal care of mature age people (estimated at \$22.0 billion per annum) and volunteering (estimated at \$16.3 billion per annum). The total value of economic and social contributions of mature age Australians using this study's methodology is estimated at \$65.7 billion per annum. The findings demonstrate that mature age Australians' contributions provide a significant offset to the often cited 'burden' of the ageing population.

The report can be accessed by [clicking here](#).

Lifestyle Intervention Slows Cognitive Decline

By [Sue Hughes](#)

Source: [Medscape Medical News](#) / Neurology—11 March 2015

Targeting multiple lifestyle factors, including physical activity, diet, vascular risk factors, and brain training, slowed cognitive decline among older healthy individuals in the first randomized, controlled trial of its kind.

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) study, published online in [The Lancet](#) on March 12, was led by Professor Miia Kivipelto, Karolinska Institute, Stockholm, Sweden.

"This is the first time that it has been shown in a longitudinal study that it is possible to reduce the risk of cognitive decline with lifestyle changes", Professor Kivipelto told Medscape Medical News.

Read more [here](#). ●

High Morale Linked to Longer Survival

By **Janice Neumann**

Source: Medscape
—24 April 2015

(Reuters Health)—Whether it is cause or effect is unclear, but high morale seems to go along with a longer life, according to a new Scandinavian study.

Among people 85 years and older, those who felt optimistic about life and had something to look forward to lived five years longer on average than their more pessimistic counterparts.

"As patients get older, their whole physical and social world gets smaller and I think that leads to fewer things they are looking forward to", said Dr Sei Lee, a geriatrician and researcher at the University of California, San Francisco, who was not involved in the study.

"Hopefully it's empowering to patients to say, as we grow older, there may be less control over our bodies and selves, but we still have control over our outlook and that actually may have a profound effect on our

mortality", Lee told Reuters Health.

Among adults in Sweden and Finland who participated in the study, all at least 85 years old, those who were most pessimistic had nearly twice the risk of dying in the next five years, compared to those who were the most optimistic. That was true even after researchers accounted for age, health and other factors.

Dr John Niklasson, a consulting geriatrician at Umeå University in Sweden and lead author of the study online March 15 in *Age and Ageing* said he was intrigued by the morale difference he had seen in elderly patients and wondered if boosting their spirits might prolong their lives.

"One day a few years ago I did medical rounds and I met an old lady, who told me, 'Doc, I don't have any reason to live'", Niklasson told Reuters Health in an email. *"She didn't say this as part of a suicidal depression, more like a dry statement",* he explained. *"A bit later the same*

morning, I met another woman of just about the same age, with about the same amount of disease and other burdens . . . she said, 'I don't have time to stay in the hospital, I have to go home today, I have so much to do.'"

Niklasson and coauthors defined high morale as *"future-oriented optimism regarding the problems and opportunities associated with living and ageing"* and used a morale scale designed for the elderly to find out if such an outlook might promote survival.

Previous research has found that people with higher morale feel better. But the authors wanted to test the theory on the very old.

They followed 646 people with an average age of 89, who lived in Northern Sweden and Western Finland, 30% in nursing homes. In 2000 to 2002, and again in 2005 to 2007, the participants answered 17 questions by phone or in person about their levels of agitation, loneliness

High Morale Linked to Longer Survival *(cont'd)*



and dissatisfaction with aging. The researchers also analyzed data from population registries to track illnesses and deaths.

In the first round of interviews, 302 people showed high morale, 203 fell into the moderate morale category and 141 showed low morale.

The elderly participants with high morale tended to be slightly younger than those who were more pessimistic and to use fewer medications. They were also less likely to live in an institution or alone, or to be socially isolated or malnourished than those with low or moderate morale.

The people with high morale were also more functional, had fewer diseases and had better vision than their pessimistic

counterparts.

At the five-year follow-up, 56% of the high morale group was still alive, compared to 32% of the low morale group and 39% of the moderate morale group. Those with higher morale were more likely to survive even after researchers accounted for age, gender, impaired vision and hearing, daily functioning and other health factors.

The researchers acknowledge that one quarter of the seniors eligible to participate in the study did not respond to questionnaires, and many of them were sicker, with a high proportion of dementia, than the study group. So the results may not generalize to all elderly people.

The study also did not measure

personality traits, which are among many factors that might affect morale as one ages.

Still, the results imply that *"if low and moderate levels of morale could be improved by appropriate intervention, it would not only improve well-being but it might also increase survival"*, Niklasson and colleagues conclude.

"It seems to me that getting your basic needs met is not enough", Niklasson told Reuters Health in an email. *"So to boost morale, other things are probably important as well: having someone to talk to, having a partner, eating good food and drink, doing things you enjoy doing and symptom relief from diseases."*

"My theory here is simply that if you lead a life you want to live, you would want to continue to live it", Niklasson said.

Lee said he was also struck by how many people in the study were depressed (62%), noting that the mood disorder is very common in older adults but often hard to detect.

"Depression just has to be very high on our list of underlying things that might be going on in (older) adults", said Lee.

Read the study [here](#) at Age and Ageing 2015. 🌟

Finding Your Feet

Pedors Australia is the exclusive national distributor for Pedors (USA) therapeutic footwear. They sell individual shoes and fit from ladies size 3 up to men's 15. Their widest fitting is a 7E so they cover an enormous range of sizes.

The material Pedors shoes are manufactured from is a neoprene blend which makes it heat mouldable and extremely light weight. The soles on all shoes are able to be modified, some come with removable spacers for moderate leg length discrepancies.

Further information is available on their website www.pedors.com.au. They have samples and catalogues available and offer free shipping and free returns Australia wide. 🌟

Pneumonia Vaccine Trial

By Marcia Frellick

Source: Medscape News—30 April 2015

News from the 25th European Congress of Clinical Microbiology and Infectious Diseases (ECCMID)

COPENHAGEN, Denmark—The 13-valent conjugated pneumococcal vaccine (PCV13) commonly used in children is effective in older adults for the prevention of vaccine-type community-acquired pneumonia and invasive pneumococcal disease, and the effect lasts for at least 4 years, according to one of the largest vaccine efficacy trials in history.

This study is *"pivotal and critically important"*, said Greg Poland, MD, director of the Mayo vaccine research group in Rochester, Minnesota, and editor-in-chief of *Vaccine*.

"I say critical because community-acquired pneumonias are common among older persons, and can be deadly, causing considerable morbidity and mortality", he told *Medscape Medical News* here at the 25th European Congress of Clinical Microbiology and Infectious Diseases.

Marc Bonten, MD, from the University Medical Center in Utrecht, the Netherlands, presented results from the Pfizer-funded Community-

Acquired Pneumonia Immunization Trial in Adults, or CAPiTA. The study [was published](#) in a recent issue of the *New England Journal of Medicine*.

The trial involved 84,496 adults 65 years and older. Half were randomly assigned to receive PCV13 and the other half were assigned to receive placebo.

"This trial demonstrated 75% efficacy against the most lethal complication — that of invasive pneumococcal pneumonia. Importantly, the PCV13 vaccine covers well over 90% of the pneumococcal types that cause this disease. And there was no evidence of waning immunity or efficacy over the 4-year period of the study", said Dr Poland.

"We will need to educate physicians — who must recommend the vaccine to their patients — on the importance of immunization", he added. *"Unlike a disease lay people have never heard of — say, HPV — pneumonia is something everyone has heard of and wishes to avoid. Among older people, they commonly hear of friends and family who are hospitalized or who died from this disease, and will be motivated to protect themselves against it"*.

25th European Congress of Clinical Microbiology and Infectious Diseases (ECCMID). Presented April 27, 2015. 🌟

Update on Vaccination Guidelines for Older Adults

Source: Journal of the American Geriatrics Society

Mark Alexander Pilkinton, MD, PhD, H. Keipp Talbot, MD, MPH
J Am Geriatr Soc. 2015;63 (3):584-588

Abstract

Vaccination is a vital component of routine preventative health. Older adults can potentially benefit most from vaccines because they have greater susceptibility to disease and associated complications. The number of infections covered and the

types of vaccines available has grown significantly in recent years. Although this represents tremendous progress, it can also result in confusion and missed opportunities to provided recommended vaccinations. This review summarizes the current guidelines for vaccination of older adults and highlights the latest innovations.

Introduction

Vaccination is the most effective way to combat the morbidity and mortality associated with infectious

disease. Current gains in understanding of vaccines have opened a wave of innovations. This knowledge, combined with a changing epidemiology of infectious agents, has led to a rapid cycle of updates to the guidelines to keep clinical practice current with scientific progress.

Generalizing vaccine guidelines for adults and implementing them in practice is more complicated than for childhood vaccines. A range of comorbidities may affect vaccine recommendations; for

Vaccination Guidelines for Older Adults (cont'd)

instance, there are no age-specific recommendations for *Haemophilus influenzae* or meningococcus vaccination, although they are recommended in all asplenic adults. There is the practical hurdle of understanding payer responsibility and reimbursement, and there is the challenge of understanding the potential benefits and limitations of a vaccine. These factors make it more demanding than ever for a provider to determine quickly within the time constraints of a routine clinic visit which vaccines, if any, to administer.

The Advisory Committee on Immunization Practice (ACIP) is

a body of medical and public health experts responsible for developing the guidelines that inform medical practice and public health decisions on vaccines. They meet periodically to discuss the latest data related to vaccine effectiveness and safety and publish detailed guidelines for individual vaccine-preventable disease.

Frequent updates to the guidelines combined with a complicated population can lead to missed opportunities to prevent infections. This review will summarize the current recommendations for vaccination of older adults and highlight the most recent changes in ACIP guidelines.

Conclusion

Treating infectious diseases is a costly endeavor associated with greater likelihood of complications in older adults. Vaccination remains one of the most effective measures to prevent disease. Recent years have seen great advances in vaccine products available and the expansion of recommendations to include more-specific populations. Table 1 summarizes the vaccines that have age-specific guidelines or risk factors that would be common in an aging population. Incorporating these guidelines into routine practice is an important step in preventative health maintenance. ●

Table 1. Vaccine Recommendations for Older Adults

Vaccine	General Recommendations	Notes
Influenza	All adults	For adults aged ≥65 intramuscular only; standard or high dose
Pneumococcal conjugate vaccine	All adults aged ≥65	Pneumococcal polysaccharide vaccine 6–12 months later
Zoster vaccine	All adults aged ≥60	Live vaccine, avoid if immunocompromised
Tetanus, diphtheria, acellular pertussis ^a	Give once to all adults	No upper age limit
Hepatitis A	No age-specific recommendation; give based on risk factors	
Hepatitis B	Give based on risk factors	Recommended for <60 with DM; consider if ≥60 with DM
Measles or MMR	Adults born before 1957 considered immune; if born after 1957, documentation of ≥1 dose of MMR	Live vaccine, avoid if immunocompromised

Mindfulness Therapy Alternative to Antidepressants

By Miriam Davis, PhD

Source: Medscape—1 May 2015

Mindfulness-based cognitive therapy (MBCT) may offer an effective alternative to drug treatment for recurrent depression, new research suggests.

Results of a randomized controlled trial, the first to directly compare MBCT with maintenance antidepressant treatment to prevent relapse in patients with at least three prior major depressive episodes, showed no difference in health outcomes or cost between the two therapies.

However, investigators note that *"when considered in the context of the totality of randomized controlled data, we found evidence from this trial to support MBCT-TS [MBCT with support to taper or discontinue antidepressant treatment] as an alternative to maintenance antidepressants for prevention of depressive relapse or recurrence at similar costs"*.

Although the investigators found no evidence that MBCT-TS is superior to antidepressants in preventing relapse, the investigators note that it may provide a viable alternative to antidepressants, allowing *"individuals to stay well and maintain a good quality of life"*.

However, Dr Byford noted that the problem now is that *"there are too few MBCT-trained therapists to whom general practitioners can refer patients"*.

Important Treatment Option

In an accompanying commentary, Roger Mulder, MB, ChB, PhD, professor, Department of Psychological Medicine, University of Otago, in New Zealand, said that despite the study's apparent negative result, the findings have substantial clinical significance.

MBCT *"might offer a similar ongoing protective effect as that of maintenance antidepressants. MBCT therefore provides an alternative effective treatment for patients who cannot tolerate or do not wish to have maintenance antidepressants"*, Dr Mulder writes.

"Depression remains a disabling condition with high prevalence and a large clinical burden. Despite the increased use of drugs, the long-term outcome of mood disorders has not improved in the modern era. Having an alternative non-medication strategy to reduce relapse is an important means to help patients with depression", he adds.

The findings were published online April 21 in the [Lancet](#).

Using Electricity to Treat Arthritis and Cancer?

Source: [Medscape Neurology](#)—12 May 2015

Bret Stetka, MD, Kevin Tracey, MD

Medscape Editor's Note: *As researchers gain a better understanding of the interactions between our nervous and immune systems, bioelectrical medicine is increasingly looking promising in treating numerous conditions, from pain to diabetes to possibly even cancer. Medscape recently spoke with Kevin Tracey, MD, President, The Feinstein Institute for Medical Research at the North Shore-LIJ Health System, Manhasset, New York, about the potential of electricity-based therapy.*

Medscape: What exactly is bioelectrical medicine?

Dr Tracey: Bioelectronic medicine is the concept of beginning with the drug target in mind rather

than the drug or device. You ask, *"What are the nerve circuits that can control that target?"*, and then identify devices or methods to act on those nerves in order to control the therapeutic target.

If you look at the history of implantable devices, most of them are based on the device itself. Only years later, or sometimes never, do we figure out exactly what the molecular mechanism of action is for the device. What we're proposing now is to say, *"Okay, let's begin with the target in mind."*

Medscape: How did you get involved in bioelectrical research?

Dr Tracey: It was an unexpected result in the lab that prompted this from the beginning. We had developed a new anti-inflammatory molecule, named CNI-1493, and we were studying its effects in the brain. Surprisingly, a

Using Electricity to Treat Arthritis (cont'd)

small amount of CNI-1493 in the brain completely blocked the release of tumor necrosis factor (TNF)—a proinflammatory cytokine—throughout the body of the animal. This made almost no scientific sense at the time. In the course of unraveling that finding, it became clear that we had come across something that was extremely important—the ability to control the drug target, TNF, by using a mechanism that was based on nerve function. The mechanism proved to be dependent upon CNI-1493 activating the vagus nerve, and signals traveling in this nerve to the body inhibited TNF production by the immune system.

Medscape: Was there prior research suggesting this relationship between the immune and nervous systems?

Dr Tracey: The results were completely unexpected and generated a series of papers in *Science* and *Nature*. What those papers did was reveal very precisely how a neural reflex circuit works to control TNF at a molecular level.

Ed Note: To read the whole of this fascinating article, click [here](#). (First, you will need to become a free subscriber with www.medscape.com)

Magnesium Deficiency

By George D Lundberg, MD

Source: Medscape—11 May 2015

How is your magnesium level? I bet you don't know. You may not think much about it. How about your various patients' magnesium levels? If you think calcium metabolism in health and disease is complicated, and I do, you ain't seen nothing yet. Try magnesium. With calcium, serum levels give you a pretty good idea as to whether the body has enough. With magnesium, not so much.

Approximately 99% of total body magnesium is located in bone, muscles, and soft tissues; 1% is extracellular. Thus, plasma or serum magnesium levels are only a rough approximation of amounts of magnesium. Substantial hypomagnesemia does indicate magnesium deficiency, but normal blood levels do not dependably exclude significant depletion of magnesium stores. We 'manage what we measure'. If we cannot reliably measure some metabolic substance, we have

far less chance of sensibly understanding or managing it.

A "Really Big Deal"

Magnesium is an essential mineral, vitally involved in more than 300 regulatory enzyme systems controlling muscle, nerve, bone, protein, DNA, glucose, and energy metabolism. Magnesium is a really big deal.

The recommended daily intake of magnesium varies by age and gender, but 400 mg is a good round number for adults. The kidneys provide homeostasis, typically excreting 120 mg/day. Since the 1960s, we have known that consumption of alcohol, even in modest amounts, can double or even quadruple the excretion of magnesium. Many over-the-counter and prescription drugs, such as proton pump inhibitors, can lower body magnesium levels.

Is Magnesium the True Emperor of All Maladies?

Magnesium deficiency has been blamed for various arrhythmias, hypertension, attention-deficit/hyperactivity disorder, anxiety, seizures, leg cramps, restless

legs syndrome, kidney stones, myocardial infarction, headaches, premenstrual syndrome, fibromyalgia, chest pain, osteoporosis, altitude sickness, diabetes, fatigue, weakness, and other maladies.

Whoaaa. Really? That is almost everything. Can that be true? Because of the vital nature of magnesium in so many cellular functions, it actually could be true. We simply do not know.

Calcium and magnesium interact in innumerable ways. Magnesium is considered 'the calming mineral'.

WHO: Americans Need to Consume More Magnesium

There has been no large systematic study of the adequacy of magnesium body stores in Americans. In 2009, the World Health Organization published a report that stated that 75% of Americans consumed less magnesium than needed. Some say that we have a nationwide magnesium deficiency. Certainly, those named illnesses are common. Obviously, the National Institutes of Health or the Centers for Disease Control and

Magnesium Deficiency (cont'd)

Prevention should fund serious work to ascertain the status of Americans' magnesium body stores, and I call upon them to do so.

For most of my professional life, I have supported the adequacy of a balanced diet and opposed the addition of nutritional supplements as unnecessary, wasteful, possibly harmful, and mostly a scam. But as the 'typical' American diet has evolved into one of fast foods and processed foods, my attitude has changed.

Eat Your Spinach, Take Supplements

Foods with high magnesium content include dark leafy

greens, especially kale, chard, and spinach; tree nuts and peanuts; seeds; oily fish; beans, lentils, legumes, and whole grains; avocado, yogurt, bananas, and dried fruit; dark chocolate; and molasses. Supplemental magnesium is available over the counter in many forms: citrate, amino acid chelate, chloride, glycinate, malate, taurate, carbonate, and others, which vary in absorption, concentration, and bioavailability.

Because you cannot just draw a blood sample and ask the lab to identify a deficiency, I advise that if a patient has any of the symptoms I listed, you might best just try that old standby,

'trial of therapy', and track what happens. Since I got interested in this topic a couple of years ago, I have emphasized the inclusion of magnesium-rich foods in my diet. Because I like to drink wine and I take occasional proton pump inhibitors, I supplement my balanced diet with an additional 400 mg of magnesium daily.

I feel terrific—better than before magnesium. I know that is subjective as all hell, but what better way would you like your patients to feel than 'terrific'? ●



Polio In Pakistan: Drop of 70% Recorded This Year

Source: bbc.com—3 June 2015

Polio cases in Pakistan have dropped by 70% this year as troops make territorial advances in the north against militants opposed to vaccination programmes, government officials have told the BBC. They say that so far in 2015 there have been about 25 cases.

In October officials said that Pakistan had its highest number of cases for 15 years, mostly due to militant attacks. At that time they said there were more than 200 cases across the country. The number in October exceeded the 199 cases in 2001 but was short of the 558 cases in 1999.

Most polio infections are in the north-western tribal region where militants have targeted health teams. They accuse doctors of being spies and say the vaccinations are part of a Western plot to sterilise Muslims.

"Army a great help"

Prime ministerial polio adviser Ayesha Raza said on Wednesday that while it had taken time to eradicate militancy in North Waziristan, the rewards from doing so were "already visible in the polio programme".

Ms Raza told the BBC that polio samples from

high-incidence zones—which used to be positive for months on end—were now testing negative again.

The Federally Administered Tribal Areas (Fata) had only reported seven cases so far this year, she said, while Karachi had reported none.

"The army has been a great help in both these areas", Ms Raza said. "With their help, and with the help of funding from the United Arab Emirates, we have been able to extend immunisation drives to high-risk areas. We got access to populations in Waziristan after more than two years. We have also now penetrated some formerly no-go zones in Karachi".

Officials say that in recent months there has also been a clear decline in the number of attacks on polio teams. A number of men involved in such attacks have been arrested.

The BBC's M Ilyas Khan in Islamabad says that while Pakistan is celebrating the latest figures, the two other counties in the world where polio is endemic have done equally well if not better.

Nigeria has reported no new cases this year, and Afghanistan has only reported one. ●