No 268 September 2018

Mornington Peninsula Post-Polio Support Group

Next meeting: Saturday, September 8, at 11am at the Information office, Mornington, cnr Main and Elizabeth Sts, rear of the building. Guest Speaker will be Kylie Knoble, Care Manager and Dementia Consultant, Southern Cross Care, Victoria. The next social outing is lunch on September 18.

For the record: meetings are held on the second Saturday of each month, with outings - lunch or dinner - on the third Tuesday unless the meeting date is mid-month.

Please contact the secretary for confirmation, venue and details, or if you need a lift.

In this edition

The survey we took part in for Deakin University made for an interesting meeting last month (p2-3).

Came across a North Carolina newspaper looking back about the treatment of polio by the Australian Sister Kenny. While Sister Kenny had some good results, her nurses were not always as proficient. That debate continues. (p4)

Small piece from Doctor Bruno about droopy eyes might strike a chord somewhere, with another of his pieces about winter and why we have suffered so much these past few months. Might have been more useful earlier, but didn't find it until now. (P5-6).

An article on global polio funding might not seem entertaining, but this one is from The Lancet and provides an insight into the health implications for millions of people with Polio in Africa and Asia as vaccination money dries up. (p7-8)

Enormous thanks to Wendy and Ian Bladon for making the trip to Mt Eliza for the council awards on a freezing night. We were kind of also-rans but made our presence known. Also don't miss our guest speaker this month: Kylie Noble. Details top of the page.

– Editor.

MPPPSG was a finalist in the Delys Sergeant Age-Friendly group awards. Certificate was presented at the community council meeting at Mt Eliza on August 28. Pictured are convenor Ian Bladon, secretary Fran Henke with Mornington Peninsula Shire Council Mayor Cr Bryan Payne. Among the many worthy group winners were Mornington Rose Garden and Hastings Community Register and men's sheds.

Contact details:
Convenor: Ian Bladon 0419 588 973
Treasurer: Bruce Worme 5981 2540
Secretary/editor Fran Henke 5979 7274
All correspondence:
48 Lyall St, Hastings, 3915

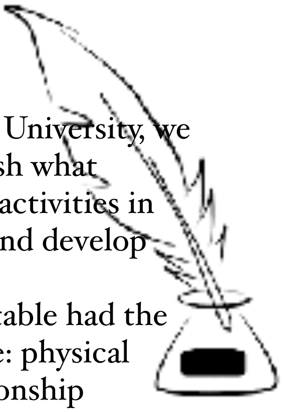
PACE Age-Friendly Communities Award
Age-Friendly Group

Age Friendly

Mornington Peninsula
Post-Polio Support Group

pace

August meeting notes



Thanks to the visit from Dr Erin Wilson and Susan Hayward of Deakin University, we had a most interesting meeting. They are conducting a survey to establish what barriers people with spinal cord injury and post-polio face in day to day activities in society. They also want to identify any changes to mainstream services and develop strategies to bring about change.

We worked through the list of service areas and everyone around the table had the opportunity to comment on those affecting them most. The topics were: physical health (GPs, hospitals, allied health); mental health; employment; relationship support; transport; environment' housing; education; ageing (age care services etc) other services. We were asked to note from one to three, the most important to us as individuals. Physical health, transport and ageing, rated highly for the group.

Naturally discussion about educating GPs, physios and others was vivid. On the subject of surgery Dr Wilson commented "the trouble is (polio organisation) has frightened everyone about anaesthetics". However, those who have had surgery in recent years have made an effort to inform anaesthetists about post-polio sensitivities and we haven't lost anyone for a while.

Andrea commented that many polios don't understand polio problems. Thanks to the newsletter she specifically mentioned understanding her own foot problems. "We need to educate the educators and educate young people", she said. "Education has to come from the top down. We need to treat doctors the way we deal with plumbers and electricians, if they don't help, get rid of them".

Bruce asked Dr Wilson if polio came up among educators. She said it was on the agenda, given the large number of cases in Asia and Africa. A map of who's teaching about polio and where was suggested.

Discussion about sleep apnoea was interesting on the difference between general and central apnoea (a sleep-related disorder in which the effort to breathe is diminished or absent, typically for 10 to 30 seconds either intermittently or in cycles, and is usually associated with a reduction in blood oxygen saturation).

Nyorie mentioned she struggled to balance keeping fit and not overdoing it. She has swum for years, but finding it harder.

Bruce commented he met a man in Japan whose job it was to create exercise for people with disabilities. Bruce told him about 'blind golf' being played at Rosebud, which excited him.

Transport: Nyorie mentioned the airport and Bruce agreed Melbourne was one of the worst 'they don't worry about you too much'. Parking was a nightmare there. 'Dragon trains' (electric carts) such as those used in China to move people around airports and public places were suggested.

Martin talked about the problem of multi-purpose taxis that cater for wheelchairs and the inconvenience of minibuses being sent that are too hard to get into and uncomfortable to sit in for a long period. He wondered if Uber was to be licensed to accept half price taxi cards.

Graeme told about his Aged Care provider going broke, leaving he and his wife without support at a critical time. He finally has had a council cleaner arrive.

Bruce mentioned how important the environment was to him. He and Barbara love feeding the great range of birds in their area and wanted to ensure council thought about this aspect of our lives. Fran agreed as her escape was the end of Hastings Jetty watching the dawn and photographing seabirds.

In discussion about the funding of the survey, we asked Dr Wilson if she was aware of the future of state government funding for organisations such as ours. She believed that State

Government funding could dry up given the amounts poured into NDIS. She said we need to watch out for NDIS funding for ILC (inclusion, linkages, connections). Secretary has written to IA to ask how best to be advised of such opportunities.

Those taking part in the survey were offered a $50 fee, members voted to donate that to the group, grateful for the interest in polio survivors by Deakin and Spinal Life Australia.

General business:

Polio Perspectives Winter edition has arrived in most letter boxes. Secretary has advised IA of those newer members whose addresses were not on the list. IA staffers are keeping an eye on grant opportunities on the groups' behalf, offering assistance with applications.

Treasurer's report:

Bruce suggested we could offer direct deposit for membership fees as a more sophisticated solution than cash in an old Christmas card. Our expenses for the coming year are covered.

Night's out

Our last lunch was well attended at the Westernport Hotel, Hastings. This seems an easy venue for cold weather but we welcome ideas for a more central, affordable and accessible place with good Seniors' meals.

Correction from Peter Charles about his surgery. (I had it back to front in the August edition). Here is the correct version:

> The tumour in my thigh involved three of the four quadricep muscles. The middle section of one muscle was completely removed, leaving only stumps of muscle just above the knee and at the top of the thigh. Normally a muscle graft from the back or other leg would be used as a repair, but in my case, a length of ligament type material was taken from the other leg and joined to the stumps. This gives less than full, but sufficient, movement of the knee, without compromising the other leg too much. The other two muscles involved lost a bit over half of their width.
>
> Apologies for the September meeting – we will be somewhere in Queensland.
>
> – Peter Charles.

Breaking news: Bruce has submitted our application for next year's grants to the Disability Self Help Grant division of DHHS and has received acknowledgement.

Further to **transport/taxi** issues, Nyorie asked about seeking funding for transport for members to meetings. Bayside Polio pays for taxis for members who might not otherwise be able to attend functions. We could do this to either from existing funds or apply to the shire for this purpose. Such an application could be well considered as a valuable community project.

Once we have donated the proposed amount of $3000 to Polio Day, this could also be a valid use of book sales money. We will need to know how many members might come to meetings or outings if transport costs were covered. Please let Fran or Bruce know what you think.

The new 'take-away' cup, fund raiser for the Network. Will be on sale at our meeting and Polio Day in October. Around $15.

Polio outbreak hit Henderson hard in 1943

Frank Boyett, Special to The Gleaner

Published 6:00 p.m. CT Aug. 25, 2018 |

AN epidemic of polio the summer of 1943 caused local schools in Henderson County, North Carolina, to postpone classes that year.

"This is the first epidemic of poliomyelitis that Henderson County has had in 20 years," *The Gleaner* reported Aug. 15, 1943, which is when it began taking notice. But it downplayed the problem, reporting that the situation was "somewhat better."

From the end of June to mid-August, the county had seen 19 cases develop locally – nine of them in the last week of July alone, which it called a "rapid and alarming spread."

What's interesting about the 1943 outbreak is that it marked a dramatic change in how victims were treated. Until then patients had confined to bed – actually strapped to boards in many cases – and placed in metal braces.

In 1940, however, a self-taught Australian nurse called Sister Elizabeth Kenny (pictured left) travelled to California and tried to get the medical establishment to take notice of the good results she had obtained from a different way of treating polio victims. She was roundly ignored.

Kenny, who earned her "sister" title as a senior British nurse during World War I, then went to the Mayo Clinic and demonstrated her method of hot-packing and stretching affected limbs. Doctors there couldn't argue with her results. In 1942 the first Sister Kenny Institute opened in Minneapolis.

Word spread quickly and *The Gleaner* of Aug. 18 noted that local patients were getting "spectacularly successful" results from the Sister Kenny treatment, which was used here for the first time.

Dr. E.W. Sigler, head of the county health department, said 10 local victims had been sent to the Kosair Hospital in Louisville, where they were receiving the full treatment. Two had already returned and "neither will be crippled," Sigler said. One was a young girl whose back had been arched like a pretzel but "now is a normal, happy little girl who is on the road to full recovery of her full strength."

Patients who stayed here received a modified form of the treatment – and Sigler was asking for donations of wool blankets to assist.

"Hot packs are made by boiling blankets for 20 minutes, giving them a quick run through a wringer, and applying them immediately to the patient. Nothing but pure wool will do. Rayon or cotton will cause flesh to be scorched." Doesn't sound like much fun, does it?

The Gleaner of Aug. 24 reported the possibility of schools being delayed. City schools were supposed to open Sept. 6 and county schools on Sept. 13, but that would be delayed if the situation had not improved. By that point there had been 26 cases of polio in the county. The next day *The Gleaner* reported classes had been indefinitely postponed for city schools at the request of the health department.

Six new cases of what was often called "infantile paralysis" were reported in *The Gleaner* of Sept. 1, bringing the total to 32. They were relatively mild compared to earlier cases.

Nevertheless, that story ended, "Appeals to parents, asking that they keep their children at home and away from crowds were renewed." Both city and county schools were set to open Sept. 20 "if no new cases of infantile paralysis are reported," according to the Sept. 9 issue of *The Gleaner*. (That story also noted that county school students would be eligible for hot lunches for the first time.)

Cont P 5

The Gleaner of Sept. 19 noted only one case of polio had been reported the previous week and that schools would open the next day. "County Health Director E.W. Sigler gave assurance last night the polio epidemic is on the wane."

According to stories in *The Gleaner* and Evansville papers, about 40 local people were stricken by polio between June and September 1943. Most of them were children; the oldest of the handful of adults was 36.

The 1943 polio epidemic was particularly bad in the western states, *The Gleaner* reported Sept. 22 – the worst since Los Angeles County General Hospital admitted about 2,500 patients in 1934.

State Epidemiologist Dr. Fred W. Caudill estimated the peak of the disease in Kentucky was the period Aug. 15-21, 1943, at which time there had been 84 cases reported statewide. "During the last two months the (Kentucky Crippled Children Commission) has admitted 36 cases to Kosair Hospital for treatment," which was the only place in the state to get the full Sister Kenny treatment.

"The majority of those cases came from Hardin, Henderson and Jefferson counties."

Polio continued to terrorise the country for another 12 years. The decade after World War II was particularly bad.

Judith Freeman, a seven-year-old, made history April 25, 1955, when she became the first Henderson County resident vaccinated against polio. A total of 1,222 first- and second-graders were inoculated at the county Health Department that day.

Also, the Sabin oral polio vaccine was administered to all local school children in the spring of 1962, courtesy of the Henderson County Medical Society and Pfizer Laboratories.

Polio was eradicated in the United States in 1979.

THE EYES HAVE IT! What the heck is "lag opthalmos."

Question to Dr Richard Bruno: I have had trouble staying asleep for years. My sleep study showed many awakenings throughout the night, but no problems with breathing or muscle twitching. I also have had dry eyes for years. My eye doctor said my eyes don't close all the way and that's why they're drying out. He said to use a sleep mask at night. When I did, I slept through the night! Were my "open eyes" causing me to sleep poorly?

Answer: I'd say so. We had been puzzled over the years by Post-Polio Institute patients whose brains awaken a lot during the night but who don't have sleep-disturbing apneas, hypopneas (shallow breathing) or the muscle twitching and jumping so common in polio survivors. It makes sense that if your eyes don't close completely while you're sleeping, any light in the room may stimulate your brain and cause it to awaken during the night, even if you don't actually wake up.

Recently, we have seen a number of patients whose eyes don't close completely, what's called "*lag opthalmos*." Some patients have daytime *lag opthalmos* and report that their eyes dry out. Others have *lag opthalmos* only at night, may have dry eyes and sleep poorly but don't know that their open eyes is the cause of these problems.

Although the poliovirus did not damage muscles inside the eye or muscles that control movement of the eyes, it could affect facial muscles. Some who have *lag opthalmos* had facial muscles affected by polio; most have no history of face muscle weakness. When we've suggest that these patients use a black sleep mask at night, they slept much better.

So if you have unrefreshing sleep or daytime fatigue, even though a sleep study shows that muscle aren't twitching and that you have no problems with breathing (or if breathing problems have been treated successfully using CPAP or BiPAP), talk to your doctor about trying a sleep mask. When it comes finding the cause of an undiagnosed sleep disorder, the eyes may indeed "have it."

Of Frozen Fingers and Polio Feet

A warming winter tale for everyone who hates the colddddddd!

From Dr Richard Bruno

POLIO survivors are extremely sensitive to changes in temperature. At merely cool temperatures, most polio survivors report that their feet have always been cold to the touch, their skin a purplish colour. However, as polio survivors have aged, 50% report intolerance to cold and that their limbs have become more sensitive to pain as the temperature decreases. Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. (Bruno & Frick, 1987).

When polio survivors were cooled in the laboratory from 86° F to 68° F, motor nerves functioned as if they were at 50° F and polio survivors lost 75% of their hand muscle strength. (Bruno, et al., 1985a) But, although polio survivors are twice as sensitive to pain as those without polio, no increase in pain sensitivity was found at lower temperatures. (Bruno, et al., 1985b)

The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the automatic computer that controls the inner bodily environment) was damaged by the poliovirus, including the body's thermostat and the brain area that tells your blood vessels to constrict. (Bodian, 1949) In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when its cold were also killed by the poliovirus. (Bodian, 1949) Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool.

When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult. As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength.

However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop (see Bruno, 1996). The pooling of blood in the feet also explains why polio survivors' feet swell, swelling that increases as they get older. And polio survivors' easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change.

Polio survivors need to dress as if it were 20° F colder than the outside temperature. The trick is to stay warm from the get-go. You need to dress in layers and wear heat retaining socks or undergarments made of a woven, breathable plastic fiber called polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm in the morning. Then put on warm socks, even electric socks with battery-powered heaters. Also, try to keep your feet elevated during the day.

Also, polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75oF to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after surgery.
(Bruno, 1996).

We must celebrate the end of polio - but the end of polio funding puts other programs at risk

Authors : Laura Kerr and Leila Stennett - The Lancet global health blog, December 2017
Laura Kerr is the Policy Advocacy Officer for Child Health at RESULTS UK. Leila Stennett is the Campaigns Director at RESULTS Australia & Secretariat of the Australian TB Caucus.

IN 1988 there were 350,000 cases of polio worldwide. So far, this year there have been 13 [written before PNG outbreaks]. The disease has gone from a global pandemic to a severe, but local, challenge.

The world has come a long way in 30 years. Over that time global coverage of the polio vaccine has increased from 65 per cent to well over 80 per cent, and at least 16 million cases of polio have been prevented.

That's 16 million children who have been spared debilitating paralysis; 16 million children who have been able to go to school, learn, get a job and contribute to society. And 16 million children who have grown up, unaware of the suffering that they might have experienced.

At the centre of these efforts is the Global Polio Eradication Initiative (GPEI) which, with a budget of more than $1 billion a year and a presence in 16 countries, has spear -headed the fight against the disease with the polio vaccine. But GPEI's work goes much further than vaccines.

Since the initiative's inception in 1988, many of the 20 million volunteers who have been trained to administer polio vaccines have also delivered other essential vaccinations and health interventions. For example, GPEI-trained health workers have delivered 1.3 billion doses of vitamin A, which have helped save 1.5 million lives and reaped up to $17 billion in economic benefits.

Funding from GPEI has also transformed monitoring of disease outbreaks through the Global Polio Eradication Laboratory Network. These 146 laboratories around the world identify and confirm cases of polio but also monitor other life-threatening diseases, such as measles, rubella, and maternal and neonatal tetanus, all major health threats in their own right. Hundreds of World Health Organisation and Unicef staff are funded by GPEI to undertake disease surveillance activities, going door to door to find and confirm suspected disease outbreaks and preventing them from spreading further. Such systems helped stop the spread of Ebola in Nigeria in 2014 while the outbreak was raging in Guinea, Liberia and Sierra Leone.

However, the GPEI was set up to achieve one goal only – the eradication of polio. As we inch closer to achieving this, the GPEI will begin to scale back its operations and with that comes a significant reduction in funding. The rate of this withdrawal is rapid. GPEI estimates its funding will drop by 50 per cent between 2017 and 2019 alone, and many of those resources are focused in just 16 countries that receive over 90 per cent of GPEI support.

Take Ethiopia for example, a low-income country where more than a quarter of children do not receive basic vaccinations. Ethiopia will lose 88 per cent of its polio-related funding between 2016 and 2019; the stark reduction from $23.5million to $4.6million between 2017-18 is already being felt. Even with expected increases in government funding, a $12 million gap exists after 2019 – putting critical elements of childhood vaccination programs against polio and other childhood killers like rotavirus and pneumonia at risk.

Many of the countries that will lose polio funding are also set to lose funding from Gavi, the Vaccine Alliance – an organisation that helps low-income countries purchase life-saving vaccines. Sudan, which has one of the highest immunisation rates in Africa, currently only funds nine per cent of its immunisation program.

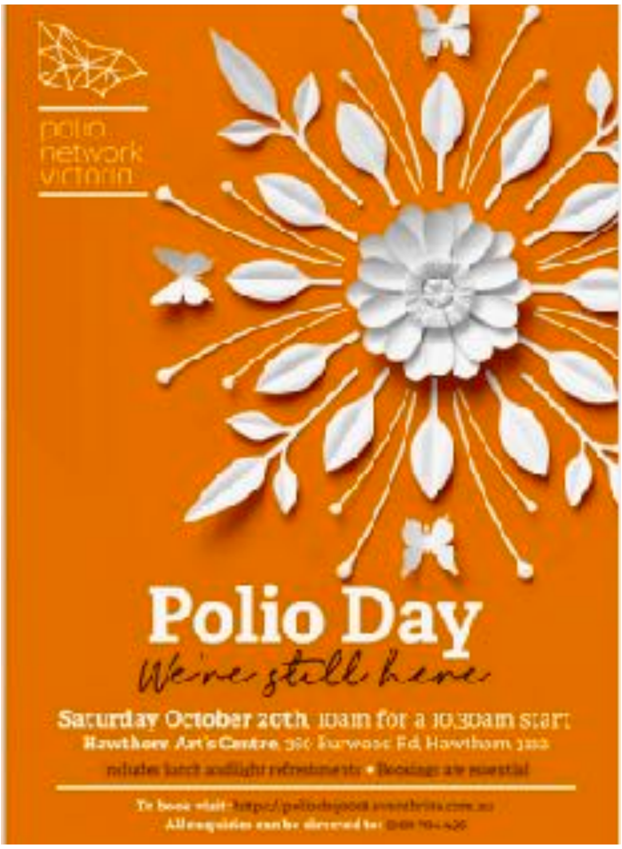
Cont P8

Under its current arrangement with Gavi, it will have to increase its share of vaccine costs from $3.1 million to $17.2 million in 2022 at the same time as losing 70 per cent of its funding from the GPEI. This double financial hit could put their high vaccination rate in jeopardy. Sharp funding reductions in short timeframes can have catastrophic impacts.

Many of the 16 countries that are losing funding now are struggling to pay for interventions and surveillance systems previously funded by GPEI and Gavi and it won't be long until some essential health programmes have to be scaled back or terminated altogether. These include essential surveillance activities, ability to respond to disease outbreaks, and any additional immunisation campaigns. I strongly believe that governments should fund health from their own coffers – overseas aid can't and shouldn't last forever. However, it is unrealistic to expect governments to magic up millions at short notice. Leadership and continued support from GPEI and donors is needed to help countries manage these changes in a gradual and sustainable way.

In another 30 years, I hope we can look back and celebrate the eradication of polio and the legacy of the global polio programme. Right now, I'm scared that we're jeopardising this legacy with poor planning and coordination, and a narrow focus on eradication.

The GPEI has helped prevent millions of cases of polio and other infectious diseases. But millions of lives could be at risk if we don't plan for what happens once we reach the end goal and when the GPEI ceases to exist. It is is the time for the GPEI, donors, and country governments to work together and map out how essential programs previously funded by the GPEI will be financed in the future, only by doing this can we ensure polio's lasting legacy.



Bookings for Polio Network Victoria's Polio Day on October 20 at Hawthorn Arts Centre are now open. Cost is $35 per head including lunch, morning and afternoon teas. Theme this year is 'We're Still Here'. Speakers are coming from State Wide Equipment Scheme and My Aged Care on navigating Post-Polio.

The aims and objects of our group are to gather and disseminate information on Post-Polio Syndrome and Late Effects of Polio, to support each other in anyway we can. Opinions expressed in this newsletter may be those of the writers only. We do not purport to be medically qualified. Consult your doctor before trying any medication or new form of exercise. Give relevant information to your doctor and help them to help us. We do not endorse any product or services mentioned.