

Mornington Peninsula Post-Polio Support Group

Next meeting: Saturday, August 11, at 11am at the Information office, Mornington, cnr Main and Elizabeth Sts, rear of the building. The next social outing is lunch on August 21. 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

LONG notes from our July meeting as we went round the table checking on how each of us were travelling. Revealed interesting challenges being faced. Also our AGM. -P2-3

We attended in force, the first information session run by Polio Australia at Noble Park and I think everyone learned something new. - P4

Recent researches came our way on sugar to aid memory and knee arthroplasty for polios, you never know when you may need to know that! - P5-6

The Polio Yarn comes from Quebec, with Ronnie Morris talking about how separation of refugee children from parents brought back ugly memories for him. Separation anxiety has been a big issue for so many polio survivors. -P7-8

One more month of winter to go, while not wishing time away, it has been cold and debilitating. Best wishes to all - Editor.



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Polio Australia's information session at Noble Park. Top: Stephanie Cantrill; above: Wendy and Ian Bladon, with Bethia Tennyson

July meeting notes

Bastille Day – and our AGM (suddenly realised, apologies to those who prefer proper warning and election details). Ian Henke who happened to be there to chauffeur the Secretary, took the chair for the election of office bearers. Results were: Convenor Ian Bladon; Treasurer and vice-chair Bruce Worme; Secretary and newsletter editor Fran Henke. Martin thanked the team and editor for the “world class newsletter”.

General meeting:

We went around the table for a ‘state of the nation’ report – how each member was travelling.

Graeme Allum has been chief cook and bottle washer following his wife’s fall, but Jan is starting to get around a bit more now. He has been struggling with My Aged Care, their provider went broke and apparently no substitute has been offered given the large waiting list.

Nyorie Linder has hired a mobility scooter, found it most useful and contemplating buying a second-hand model, ideal for dog walking.

Martin Fisher has found his MAC cleaning helpful and a stretching routine valuable. He had five visits to a physio – who knew nothing about polio. He exercises at home now, finding the bus trip to the pool hard work.

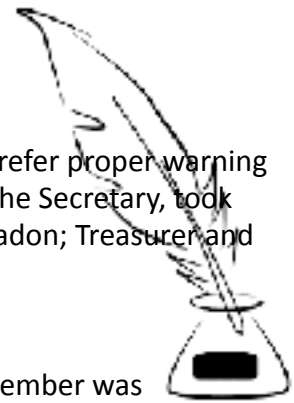
Peter and Marie Charles – Peter is out walking following surgery to remove a tumour on his leg. Pleased with his recovery. Peter has become a guinea pig for the way a piece of muscle was used rather than tendon. He does not have as much leg strength now. However, a film has been made about his surgery to show other surgeons how not to compromise the ‘donor’ leg. The Charles and Martin have visited Keith Ashford in the nursing home (where Audrey was) and found him keen to have visitors.

Martin says: “I paid Keith a visit this afternoon and yes he is staying at the Regis Shelton Manor – 93 Ashleigh Ave Frankston Vic 3199 – phone number 03 9789 6999. He is in the Sheraton wing, room 16. He was having a light snooze in his chair when I arrived but after a gentle knock on his door his eyes popped open and he was very pleased to see me. He was telling me that as a result of a stroke he was found unconscious in his hallway and when he woke up he was in hospital. We chatted for some time. His speech is a bit slow but his mind seems ok. He is going through the process of permanent accommodation at the REGIS. If anyone would like to pay him a visit it would be best to ring to check that he has no medical appointments at the same time. He has received the newsletters. Anyone can send a get-well card to Keith Ashford at the address above.

It would appear that most friends and relatives who visit the REGIS MANOR in Frankston, do so in the morning because the small car park is usually full up and you will have to park out on the road. So, if you have mobility issues it would be best to visit during the arvo. Also, enquire at the front desk regarding the pin number you will need to open the front door when you leave. REGIS residents have their evening meal at 5pm – YIPES !!!”

Marie Tilden has had a lot of problems with arthritis in recent months, having a bad reaction to the injection. She had her ankle fused three times because cartilage had worn out. She also raised the issue of disability taxi problems. Her walker was thrown in the back of one van (not secured) and rattled around for the entire journey. She found when a van comes rather than a sedan, she finds it really difficult to get in and out and most uncomfortable on the narrow seating.

Mike Bastone is experiencing severe fatigue as result of prostate cancer treatment over the past two years. Said he was coping ok but had back ache when sitting in chair and lying down.



Bill Crosbie also had back problems and was seeing a chiropractor. He had one shoulder sitting lower than the other but was better after treatment. Blood tests showed he was lacking in B12 and is having an injection regularly to compensate. Bill said he was not able to do much mowing any more (at 80+) and tires easily after gardening for three hours (!). To deal with wind coming off the sea he ensures he wears a scarf.

Bruce Worme is continuing treatment and scans. His aneurism has shrunk (good news). One of the scanners asked about his brace so was immediately informed about polio. He cannot hear much without hearing aids, one of which 'sang' to us throughout the meeting.

Fran Henke recently turned 75, she and Ian had a tough winter with bronchitis. But was celebrating a rich life. Peninsula Essence has done a profile of her, published this month (August).

Ian Bladon was over the flu at last. He told of seeing the psychologist at PNV which was most useful. He was enjoying too much the beautiful recliner Wendy gave him, so the psych suggested gentle exercise and asked if he had kept in touch with old friends, recommending he telephoned a few people. This he has done. Ian's session prompted asking manager of the Psych team for a couple of articles on winter isolation and depression for the Winter edition of Polio Perspectives, out soon.

General business: continued the discussion about multi-purpose taxis. Martin and Marie recommended when calling for a taxi, insist that you do not want a van, preferring a sedan. Martin said Silver Top had outsourced its call centre to South Africa. Uber may be introducing disability friendly taxis but not expected to take the half price card.

Marie said she took a taxi from the airport to Mornington, with an African driver who was most agitated he wouldn't get a fare back. She rang the complaints number but found the complaints officer had less English than the driver! Martin said the Ombudsman was very good. If a driver is rude, make a note of the driver's number.

Treasurer's report: Bruce said it cost us around \$1700 annually to run the group, with room hire, newsletter costs (cartridges, postage, paper etc). The grant from State Government is \$3652 over two years. Our other income is in membership fees, due now (\$10 pa). Bruce emailed later that six members had sent fees, while those attending paid on the spot.

Income from Life Skills was \$1150 this year. We have already donated \$2500 to PNV and hope to make another donation before Polio Day 2018. In the original proposal, we estimated that on sales of 250 we could donate \$3000 to PNV for Polio Day. Given that around 90 of the 300 print run have been given away to worthy people, and the reprint of a further 100, we will be on track for that donation.

Further sales can be made at Polio Day 2018 in Hawthorn (October 20) and at the Polio Australia retreat in South Australia, also in October. Meanwhile, 10 books have gone to NSW for the Central Coast polio conference in September (IA covered postage) with arrangements to come back to our account. A further \$31.84 has come back from PayPal from Random Harvest for e-sales for the past six months.

Lunch report: great turn up at the Westernport Hotel with Bethia, Lois and friend Beth, Ian and Wendy, Marie, Ian and Fran, Graeme and Jan (delighted to meet her at last after a rough trot). Bill sent apologies, he had to attend a funeral.



Number plate surround with a good message. Image thanks to Karen Delugas Sebastian

Polio Australia's First Information Session

OUR group was delighted to meet Stephanie Cantrill at our June meeting where she explained the role of Community Development Officer funded to help find polios who have not come forward.



PA's Mary-ann Liethof, Rachel Ingram and Stephanie Cantrill at the first information session, Noble Park

The first information session was at Noble Park on July 27 and well attended by MPPPSG members, also Knox Yarra Ranges, South Eastern Region and the Polio Australia team with Mary-ann Liethof and Rachel Ingram, Health Promotions Officer.

Seemed to be two new people, one asking particularly about anaesthetics. Stephanie's Power Point presentation was specially developed for the sessions, going from polio historically, to the late effects symptoms.

No matter how many times you see something like that, subjects relating one's own current condition can particularly resonate – such as respiratory issues. Lyn Bates (SER convenor) said that Monash Health has a respiratory support unit. It requires referral.

A question about bone scans (osteoporosis) raised the point of

ensuring you have both sides scanned, or if unable to get out of a chair, both arms. Exercise: Stephanie made the point that shopping, gardening and housework counts as exercise. Psycho-social effects of having had polio – the 'just get on with it mentality' can mask real problems. Independence Australia has an excellent team of psychologists, led by Dr Andrew Sinclair. Make an appointment if baggage is too heavy.

She also spoke about navigating the system, and how hard that can be. Dealing with NDIS, My Age Care, continuity of support issues can cause real stress and confusion.

Lyn mentioned she has been assessed twice and refused twice, advised to go into a nursing home. One assessor did not understand what a ceiling hoist was – the device lifting her in and out of bed.

Stephanie made the point that when being assessed, talk about what happens on your worst day, not the best. And if asked how many falls you've had recently – define falls. Does not necessarily mean falling, breaking, smashing. It can mean trips and saves.

Don't wait until you think you need a support package, given the waiting list, apply now. Private Health – do not pay for it, if you're not getting enough out of it. Ask does it cover orthotics?

The next session is at Ballarat on August 23, at the Sebastapol Bowling Club from 1.30-3pm.



Slide from the presentation - famous polio survivors. How many can you name?

A spoonful of sugar can help memory – research

- A small dose of sugar can improve memory in older adults, motivate them to work harder and puts them in a good mood when performing difficult tasks
- Researchers gave participants a drink containing a small amount of glucose and got them to perform memory tasks – found improvements in memory, mood and level of engagement
- Short-term energy in the form of raised blood sugar levels could be an important factor in older adults' motivation to perform a task at their highest capacity

Led by PhD student Konstantinos Mantantzis, Professor Elizabeth Maylor and Dr Friederike Schlaghecken in Warwick's Department of Psychology, the study found that increasing blood sugar levels not only improves memory and performance, but makes older adults feel happier during a task.

The researchers gave young (aged 18-27) and older (aged 65-82) participants a drink containing a small amount of glucose, and got them to perform various memory tasks. Other participants were given a placebo – a drink containing artificial sweetener.

The researchers measured participants' levels of engagement with the task, their memory score, mood, and their own perception of effort.

They found that increasing energy through a glucose drink can help both young and older adults to try harder compared to those who had the artificial sweetener. For young adults, that's where it ended, though: glucose did not improve either their mood or their memory performance.

However, older adults who had a glucose drink showed significantly better memory and more positive mood compared to older adults who consumed the artificial sweetener. Moreover, although objective measures of task engagement showed that older adults in the glucose group put more effort into the task than those who consumed the artificial sweetener, their own self-reports showed that they did not feel as if they had tried any harder.

The authors concluded that short-term energy availability in the form of raised blood sugar levels could be an important factor in older adults' motivation to perform a task at their highest capacity.

Heightened motivation, in turn, could explain the fact that increased blood sugar levels also increase older adults' sense of self-confidence, decrease self-perceptions of effort, and improve mood. However, more research is needed to disentangle these factors in order to fully understand how energy availability affects cognitive engagement, and to develop clear dietary guidelines for older adults.

Konstantinos Mantantzis, a PhD student from the University of Warwick's Department of Psychology, commented: "Over the years, studies have shown that actively engaging with difficult cognitive tasks is a prerequisite for the maintenance of cognitive health in older age. Therefore, the implications of uncovering the mechanisms that determine older adults' levels of engagement cannot be understated."

Dr Friederike Schlaghecken, from the University of Warwick's Department of Psychology, commented: "Our results bring us a step closer to understanding what motivates older adults to exert effort and finding ways of increasing their willingness to try hard even if a task seems impossible to perform."

The paper, 'Gain Without Pain: Glucose Promotes Cognitive Engagement and Protects Positive Affect in Older Adults', is in press in Psychology and Aging. It is co-authored by PhD student Konstantinos Mantantzis, Professor Elizabeth Maylor and Dr Friederike Schlaghecken at the University of Warwick, UK.

Outcome of total knee arthroplasty in patients with poliomyelitis: a systematic review.

Abstract

Total knee arthroplasty (TKA) in patients affected by poliomyelitis is technically challenging owing to abnormal anatomical features including articular and metaphyseal angular deformities, external rotation of the tibia, excessive valgus alignment, bone loss, narrowness of the femoral and tibial canals, impaired quadriceps strength, flexion contractures, genu recurvatum and ligamentous laxity. Little information is available regarding the results and complications of TKA in this challenging group of patients. We carried out a systematic review of the literature to determine the functional outcome, complications and revision rates of TKA in patients with poliomyelitis-affected knees. Six studies including 82 knees met the inclusion criteria and were reviewed. The mean patient age was 63 years (45 to 85) and follow-up was 5.5 years (0.5 to 13). All studies reported significant improvement in knee function following TKA. There were six failures requiring revision surgery in 82 cases (7%) occurring at a mean of 6.2 years (0.4 to 12). The reasons for revision surgery were aseptic loosening (17%, n=1), infection (33%, n=2), periprosthetic fracture (17%, n=1) and instability (33%, n=2). Thirty-six knees had a degree of recurvatum pre-operatively (44%), which was in the range of 5° to 30°. Ten of these knees (28%) developed recurrent recurvatum post-operatively. The findings support the use of TKA in patients with poliomyelitis-affected knees. The post-operative functional outcome is similar to other patients; however, the revision rate is higher. Quadriceps muscle power appears to be an important prognostic factor for functional outcome and the use of constrained implant designs is recommended in the presence of less than antigravity quadriceps strength. Cite this article: *EFORT Open Rev* 2018;3:358-362. DOI: 10.1302/2058-5241.3.170028.

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Health and Wellness Retreat Polio Australia 2018

Polio Australia is hosting its eighth annual retreat on the beautiful Glenelg Beach in South Australia. This retreat focuses on 'Body, Mind & Spirit', encompassing a range of self-management strategies for polio survivors and their carers.

Date: Thursday, October 11 – Sunday October 14

Location: Stamford Grand Adelaide, 2 Jetty Rd, Glenelg

Cost: \$450 per person for twin share/double occupancy OR \$500 per person for single room occupancy. This cost is all-inclusive.

Who can attend? Polio Australia encourages all polio survivors to attend, family, friends and carers. This retreat is valuable for all attendees.



Separating children from families - again

Detroit free press, June 24, 2018

WHEN Ronnie Morris heard the cries from immigrant children being separated from their families at the U.S. border, memories of his own painful childhood in isolation with polio came rushing back to him.

"It went right to my soul. Right to the deepest part of me," Morris, 69, of Grosse Ile (Quebec, Canada) said, his voice at times, cracking. "I saw these kids and I cried the whole night. I know what's coming for these children."

The Trump administration's zero-tolerance immigration policy has separated more than 2,300 children from their parents or families at the U.S./Mexico border, where thousands have come over the last several months seeking asylum.

After a groundswell of public outrage against the detention of children without their caregivers, President Trump signed an order Wednesday pledging the government will cease separating families detained at the borders, but his administration has not clarified whether it will reunite separated children with their parents, leaving the children in limbo.

Many healthcare professionals are deeply concerned about the children who were separated and now living in foster care in different parts of the country, including dozens of children in Michigan. Experts say the family separations of immigrant children are harmful psychologically and physiologically — and could be damaging to them for the rest of their lives.

"At the very least, it's terrifying for them," said Robert Fink, a clinical psychologist and professor of counselling at Oakland University. "Many of these children and families were already exposed to very frightening, dangerous situations, which is why they were making the migration north."

Morris agrees, and offers his story as evidence.

Doctors diagnosed Morris in 1951 with what, at the time, was known as infantile paralysis. A polio vaccine was not yet available, and at two years old, Morris said he was taken to the hospital, placed in isolation to keep others from getting sick.

When he was no longer contagious, Morris said he went to a rehab centre, away from his parents and older sister, for eight months. That separation, he said, left him with lifelong anxiety, flashbacks, and emotional pain.

"It's something that stays with you your whole life," Morris said. "These kids are never going to be right."



Ronnie Morris, still suffers PTSD from being separated from family as a child with polio.

Needless and cruel

When Morris heard audio recordings of 10 children wailing and sobbing, asking, in Spanish, for their "Mami" and "Papa" after they were separated from their parents by immigration authorities, it triggered heartbreaking memories. He said there was a lot of crying and emotionally wrecked children in the centre he stayed in as a boy.

His parents, who had moved from Kentucky to work in the auto factories, only saw him when he was in rehab on Sundays. He was allowed to go home just for Christmas, but by then he said, he had been away from his family so long he had forgotten them.

"When I returned home the following Easter, I didn't speak or know how to love my mother or father," he added. "I'm going to be 70 years old this November. I still suffer from intense PTSD from this experience. I still have nightmares. Travel was always traumatic."

Morris said he recognises that unauthorised border crossings may be illegal. "Should there be consequences?" he said. "Yeah." But, he added, he also identifies with the immigrant families and their efforts to make a better life.

In his own life, he said, he has not only survived polio, he also earned a bachelor's and a master's degree, got married, had children and grandchildren, worked for Ford for 30 years and published a novel.

"What they did is no different than what my parents did," he said of immigrant families. "My parents came up from the South to seek a better life to get away from working in the coal mines, better health care, more opportunity and more opportunity for their children."



Illustration by Michael Byers called '*When Polio walked the earth*' - still does mate!

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.