



MEDIA RELEASE

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We're still here: Hope and help for Polio Survivors in SA

Now eradicated in the western world and most of the rest of the globe, Polio is often thought of as a disease of the past. But for the estimated 400,000+ Australians who have ever had Polio, the fight is far from over.

This month is Polio Awareness Month, and while the campaign to end polio continues worldwide, here in South Australia work is happening to create hope for those living with the late effects of Polio, or Post-Polio Syndrome (PPS).

Polio SA member Ron Blackwell contracted Paralytic Polio in 1948 at the age of 9. Living in a small South Australian country town, at that time Ron was the only person affected with the paralytic form of the disease.

"I was away from home [in Hospital] for twenty months and on my return it was almost like it hadn't happened from the point of view of other people. I went back to school and my mother insisted on me wearing long trousers to cover the supports I wore. I played sports and did a lot of different activities, so it didn't have the impact on me that I'd seen in others who contracted it younger, while their bodies were still developing – they were more extremely affected."

Ron enjoyed what he describes as 'pretty decent health' up until his mid-40s, when he started to experience difficulties related to his past Polio infection. "The difficulties I started having resulted in Depression – that really stemmed from frustration, suddenly not being able to do what you think you *should* be able to do", says Ron.

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Now in his late 70s, Ron's biggest challenge is fatigue. "It's a bit of a compromise really, as you need to exercise to keep your muscles in good nick. I am involved in a lot of activities but have to be wary of the fact that with the fatigue present I can easily overdo it."

Weakness and fatigue, and increasing or new pain in either polio-affected or non-polio affected muscles are key features of Post-Polio Syndrome (PPS). PPS can occur at any time post-polio, but tends to be more noticeable as people begin to age, says Dr Nigel Quadros, Senior Consultant, Rehabilitation Medicine at The Queen Elizabeth Hospital and a specialist in PPS.

"It's vital that people who think they may be experiencing PPS get a proper medical evaluation to identify and treat reversible causes of fatigue and weakness, such as diabetes, or thyroid disease", says Dr Quadros.

The first step is to go to your GP and discuss your problems. There are specialised approaches to treating Post-Polio, and GPs and other health professionals treating post-polio patients can access clinical guidelines available online from Polio Australia".

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The main advice: following a healthy diet, losing weight, and practising energy conservation - doing tasks you are able to do, knowing your limits and having frequent breaks.

“Many polio survivors were real go-getters – they had to prove as youngsters that they could keep up, and to find that suddenly they can’t anymore can be difficult”, says Dr Quadros.

“It’s important for those around them to understand their limitations and provide them with support and understanding.”

Polio SA operates a support group providing information and practical support – including low cost physio and hydrotherapy - for people experiencing the late effects of Polio.

Yen Tran, 57, contracted Polio in Vietnam c.1960, when she was aged just 9 months. “Polio has caused problems for me my whole life... often people who contracted Polio overseas were affected when very young. We just had to get on with our lives”, says Ms Tran.

“As I’m getting older my muscles are getting weaker so I looked for help from the physio, and they suggested I join Polio SA.

“It’s good to know that around you there are people with similar problems. There’s a network, and we get information from professionals about how to manage our condition better, and conserve your energy to be able to do the things that are important to you rather than let the condition run your life”.

Through Polio SA, Yen and Ron stay in touch with the latest research into PPS, such as the study currently being planned by a team from the University of Adelaide’s School of Medicine’s GTRAC (Geriatrics) centre and the Queen Elizabeth Hospital. This non-invasive study has recruited 30 participants and is seeking further volunteers.

“As we age, everyone experiences a reduction in physical strength and increasing frailty – known as ‘sarcopenia’. It’s a normal part of ageing, and in most people its progression can be delayed with a healthy diet and exercise.” says principal investigator, Dr Kandiah Umaphysivam (Sivam).

“But where people have an existing neurological disability like Post-Polio Syndrome, their capacity to exercise is reduced.

“Our study aims to better understand how sarcopenia affects people with Post-Polio, compared with the ageing process in someone without post-polio. This is the first step towards developing a screening tool, and identifying which types of exercise, dietary changes and other wellbeing interventions work best to keep people with PPS active and healthy for longer”.

For now, there are a number of steps people who have ever had Polio can take to keep fighting the disease and improve their quality of life.

“If you’ve ever had Polio the first thing to do is visit www.poliosa.org.au and join Polio SA”, says Brett Howard, President of Polio SA.

“Registering is free, and will keep you up to date with the latest information, Polio research and news by email. There’s no pressure to come to meetings or events – unless you want to.”

Membership costs \$15 per year, and includes access to an hour of free hydrotherapy every week, up to six free massage vouchers each year, and a quarterly printed newsletter.

“Polio has caused problems for me my whole life... often people who contracted Polio overseas were affected when very young.

“We just had to get on with our lives”. – Mrs Yen Tran

“It’s important for all people who’ve ever had Polio to be counted...we’re still here.” – Brett Howard

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Polio SA encourages everyone who has ever had Polio, whether contracted in Australia or Overseas, to be counted on the Australian Polio Register.

Managed by Polio Australia, the register numbers 2,857 people of the estimated 400,000+ people in Australia who've ever had Polio. Polio survivors can request to be added when joining Polio SA, or register directly with Polio Australia at <http://www.australianpolioregister.org.au/register-today/>

"It's important for all people who've ever had Polio to be counted", says Brett. "After the vaccines were introduced, many medical records about Polio in Australia were destroyed – it was assumed it was all over".

"But we're still here."

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Interviews and photo opportunities on request, with:

- Ron Blackwell, Polio SA committee member and polio survivor
- Brett Howard, Polio SA president and polio survivor

ABOUT POLIO SA: www.poliosa.org.au

Polio SA is a not for profit organisation operated by volunteers. All staff and members have had polio or have a family relative diagnosed with post-polio syndrome (PPS). PPS is the late effect of polio, usually occurring 20 to 40 years after the initial infection. Not all people who previously had polio will experience new symptoms.

Our aim is to:

- provide information about the late effects of polio and PPS to members and the greater community
- provide a supportive network through consultations, referrals and social gatherings, and
- ensure that Polio SA members are aware of their rights regarding their disability.

We provide the following services:

- mutual support through group meetings
- access to discounted health services including massage and hydrotherapy (see our website for details of current services)
- newsletters keeping members up to date with local and international developments
- access to a wide range of relevant information, and
- connecting people with similar interests.

Country groups Previously there were polio support groups in rural South Australia, however to our knowledge these are no longer active. All Polio SA resources are available to our rural members, including books, fact sheets, past newsletters, and personal stories.

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Further information about the GTRAC study *Prevalence of sarcopenia (muscle loss) and frailty in post-polio patients*

Project Title	Prevalence of sarcopenia (muscle loss) and frailty in post-polio patients
HREC Approval Number	Q20170810
Principal Investigator	Dr Kandiah Umapathysivam
Associate Investigators	Dr Nigel Quadros, Dr Anupam Datta Gupta, Assoc. Professor Solomon Yu and Professor Renuka Visvanathan
Location	The Queen Elizabeth Hospital (TQEH) and Basil Hetzel Research Institute (BHI)

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