

*Quarterly*NEWSLETTER

Issue 135 Spring 2019

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Polio SA

The post-polio support group for South Australians

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poliosouthaustralia

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Letters of general interest will be published in future issues as space permits. We reserve the right to edit all letters for reasons of space and clarity. We will withhold your name upon request, but no unsigned letters will be accepted for publication. Opinions expressed in letters do not necessarily reflect the views of Polio SA Inc.

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From the President

A successful AGM

I will be really glad to feel the warmth of the sun again, after another chilly winter, my least favorite season of the year. We had 30 Members attend this year's AGM on a very wintery Sunday in August. I am pleased to tell you that your existing Committee will continue to support you for the 2019-2020 year. The Committee would also like to thank the attending Members for their positive contributions to the Meeting. I thank the Committee for their continued support and look forward to some more successful advances in the support of polio survivors in South Australia. The Committee consists of Trevor Jessop, Secretary; Peter Wierenga, Treasurer; Ron Blackwell, Jo Gordon, Charles and Julia Greeneklee and Maureen Kowalick. The great work being done by Helen by reaching out to existing Members and new members has increased our Membership and the information being disseminated to Members. This work has taken a lot of duties from the President and Secretary and is much appreciated.

Sarcopenia with Polio Survivors

After the Business of Polio SA was completed once again, Dr Nigel Quadros and Dr Sivam reported on the progress of their Project on Sarcopenia with Polio Survivors in South Australia. Dr Nigel has presented his papers to Rehabilitation Conferences in Auckland and Kobe and will present in Krakow and in Adelaide in September and October. Dr Nigel also told us of the In-patient Clinics at the Griffith Hospital available to Polio Survivors and several of our Members have already had the benefit of attendance at these sessions. Dr Nigel also has some plans to increase availability of Post-Polio Services to a wider section of survivors as well as reaching out to CALD people.

Poetry and Irish wit

We were then entertained by some very quirky poetry with a bit of Irish wit giving a slant to Aussie yarns which was great to hear. Thank you very much to Jill Wherry, a pleasant interlude. Polio Survivor from Sudan, author Esther Simbi, gave us a short precis of her life which is detailed in her book, "Beyond Calamity". I am assured it is a very interesting read which I will catch up on it soon.



The afternoon concluded with a pleasant cuppa and chinwag with those present. The ninth and last Polio Australia Health and Wellness Retreat will be held at the venue of the very first Retreat, **St Joseph's at Baulkam Hills suburb of Sydney**. The Retreat will run from 17th-20th October 2019 and positions are filling fast so please think about attending and contact Polio Australia

https://www.polioaustralia.org.au/retreat-2019/

Brett Howard, President Polio SA:

Bracing for Polio Survivors

Question: The knee on my polio leg kept bending further backward over the years. I was told to get a brace but didn't want one until I absolutely had to have it. After a while my knee hurt so much I've finally got a brace. But my knee bends so far back now that the brace bites into my skin and is so painful I can't wear it. Even if I could wear the brace, it is so heavy I can't lift my leg. What can I do?

Dr. Bruno's Response: Unfortunately, it's too late for a brace to help. Braces are designed to support a weak leg, not to fix mechanical problems like recurvatum ("back knee"). We have seen many braces that hurt too much to wear because they were intended to "fix" recurvatum or to straighten a foot that has turned outward for 40 years. All braces should be designed to fit your leg just as it is, not to make it look the way other peoples' legs do, which leads to a Post-Polio Precept: never brace to fix a deformity!

Many polio survivors have come to The Post-Polio Institute with braces that are unusable because they are too heavy, made with the 1940's vintage steel, aluminium metal uprights, contain way too much plastic or have ankle joints. The Post-Polio Institute patients do very well with the new lightweight braces that use plastic moulded to the shape of your foot and leg to replace the metal uprights.

The most common brace worn by polio survivors is the short leg brace, the moulded anklefoot orthosis (MAFO). It is made of a relatively thin plastic that slips into your shoe and goes up the back or front of your lower leg to stop foot drop, give a spring to your step if you have weak calf muscles, and even support a weakened thigh muscle to help prevent the knee from buckling. The brace you were prescribed, the long leg brace or knee-ankle-foot orthosis (KAFO), usually replaces the metal uprights with moulded plastic that slips into your shoe, goes up the back of your lower leg and is attached to a plastic cuff behind your thigh with a metal hinge and lock at the knee. Uprights can be used in place of plastic but are now made of graphite -- a super-strong, ultralightweight but very expensive composite material used in airplanes -- if you need extra support or if your leg twists too much to be comfortable in a moulded brace. There are now two types of KAFO knee joints: the old, familiar joint with drop-locks ("Bale" locks) or

a spring-loaded latch that prevents the knee from bending when you stand and walk. A newer development, the offset joint, can be used by those who have some strength in their quadriceps and whose knees bend backward at least a little. The offset joint doesn't lock, but it still prevents the knee from bending when your leg is straight. With the offset joint you can swing your leg normally when you walk but be secure when you're standing.

However, polio survivors should avoid ankle joints, be they plastic or metal, which prevent your foot from dropping but allow your ankle to bend upward. Hinged ankles add weight to the brace, take away support for weakened thigh muscles and prevent the brace from helping your leg to spring forward. I'm sorry a brace can't help you. We have unsuccessfully tried to brace other polio survivors with severe recurvatum.

They, too, couldn't wear a KAFO because it hurt too much. Instead, they needed to use crutches or a wheelchair, which raises two important points: waiting until you're ready" or until *Bracing A Bruno Byte* © www.papolionetwork.org 2018 you "have to" before using an assistive device is waiting too long; and, even if you are willing and able to use a brace, you will also need to use a cane or crutches. How do you know which to use? The rule of thumb is: if you use a MAFO, you also need a cane; if you use a KAFO, you need two forearm crutches.

If you have a brace on one leg, a cane in the hand on the opposite side shifts your weight away from the weaker, braced leg. Using two forearm crutches with a KAFO takes the load off your stronger leg as well as overused hip and lower back muscles on both sides. But there's problem. Canes and crutches put a strain on your hands, arms and shoulders and can cause carpal tunnel syndrome and upper body pain and muscle weakness. How do you save your arms? By using a wheelchair, especially outside the house.

To walk is painful, to roll divine.

A Bruno Byte

from

Dr. Richard L. Bruno, HD, PhD Director, International Centre for Polio Education.

Should Polio Survivors do Exercise for Strengthening?

Question:

In January I shovelled snow and my left leg became very weak. My knee buckled twice but I caught myself before I fell. I went to my doctor and he sent me right to physical therapy. In the first session I was on the treadmill for 10 minutes, on the bike for 5 and I did straight leg raises with weights around my ankles. I barely made it home, where I fell to the kitchen floor. My legs are even weaker now and they are always burning. Don't polio survivors need exercise to make weak muscles stronger?

Dr. Bruno's Response:

Your body is answering that question for you, but let me tell you about the research regarding exercise and polio survivors. There have only been about half a dozen small studies that tested around 12 subjects each. And although 90% of the subjects were said to have "Post-Polio Syndrome" or reported new muscle weakness, their legs were much stronger than yours. Subjects were able to ride a bike for 5 minutes and then do straight leg raises multiple times with a weight attached to the ankles 2 to 4 times a week for from six weeks to two years -- something you couldn't do one time.

The studies tested polio survivors' ability to strengthen their quadriceps muscle, the muscle in the front of your upper leg that allows you to kick your lower leg up while you're sitting and to "lock" your knee when you're standing. The quadriceps is the muscle that gave out when you fell in the kitchen. The studies differed in the way exercises were performed. Two studies asked polio survivors to limit the number of leg lifts if they felt fatigue, told them to rest between bouts of exercise and increased the amount of weight lifted only if there was no "excessive fatigue." Other studies described their exercise regime as "high-intensity," "heavy resistance," or "aggressive."

Two studies required polio survivors do five minutes on an exercise bicycle before they did as many as 30 leg lifts three times each week. In the most aggressive study polio survivors did five minutes on the bicycle followed by a 60 minute exercise class twice a week for 5 months! A polio survivor who is able to do that kind of exercise clearly does not have PPS! The subjects in the studies had more strength, more endurance, more ability to function and fewer symptoms than you do or do the patients we treat at The Post-Polio Institute. Still, when you read the researchers' conclusions it sounds like exercises is just

the thing to restore muscle strength in polio survivors with PPS. Said one article, "...a supervised training program can lead to significant gains in strength." Unfortunately, when you look at the study's actual data, the benefits of exercise are far from clear. Only 53% of those who exercised had an increase in leg muscle strength of about 26%. About one quarter of the subjects had no change in strength while 21% had a decrease in strength of about 10%. So, more often than not, exercise either had no effect or actually decreased muscle strength. But there's more. Well, actually less.

Only three studies asked whether exercise had an impact on polio survivors' ability to function in their daily lives. In one study where exercise was limited by fatigue, there was no measurable change in muscle strength over 2 years, although half of the subjects thought their walking and stair climbing had improved. In one aggressive study there was a *Should Polio Survivor's Exercise for Strengthening?* A Bruno Byte © www.papolionetwork.org 2016 2 29% muscle strength increase, no improvement in subjects' ability to do their daily activities, but an increase in muscle fatigue of from 150% to 300%! Muscle fatigue also increased by 21% in another aggressive study in which strength increased by 36%.

You have to ask what good comes from any small increases in muscle strength that are not related to improved functional ability but are related to muscle fatigue that increases more than strength does. Dr. Alan McComas' performed a study showing that polio survivors who were not treating their muscle weakness and were getting weaker lost 7% of their motor neurons each year. McComas concluded that "polio survivors should not engage in fatiguing exercise or activities that further stress metabolically damaged neurons that are already overworking." Muscles weakness is a sign of neurons failing and dying. Polio survivors were taught to "use it or lose it" and to exercise until you "feel the burn." When you feel the burn you are burning out your neurons. The Bottom Line: Should you do exercise to strengthen newly weakened muscles? No!

A Bruno Byte

from

Richard L. Bruno, HD, PhD Director,

International Centre for Polio Education

Paralympic Swimmer Elizabeth Edmondson



Paralympic swimmer Elizabeth Edmondson's 1964 Tokyo Games record still stands 55 years on . At just 14, Elizabeth Edmondson became the youngest Australian to claim an individual gold medal for swimming at either an Olympics or Paralympics. It is a record that still stands today.



Elizabeth (left in picture) who had been diagnosed with polio when she was just 15 months old and spent a year in hospital.

Continued next page.....

The Tokyo medals

Elizabeth's medals from the 1964 Tokyo Paralympics are proudly displayed in her home, framed alongside pictures of her competing at various events.

But if not for a slice of luck, she may not have made it to the Games at all.

"I started swimming in January of 1964 with my sister. We trained at Tony Howson's pool at the Commonwealth Games village in City Beach," she said.

"I think he only had a 12.5-metre pool and after two weeks he said come and train with the squad at Beatty Park, which had opened for the Commonwealth Games in 1962.

A chance encounter

It was there that Edmondson, who had been diagnosed with polio when she was just 15 months old and spent a year in hospital, caught the eye of Howson's wife.

She was a physiotherapist who worked for Sir George Bedbrook, the founder of the Paralympic movement in Australia.

"That's how I found out about the Paralympics, through Tony's wife," Edmondson said.

"When I had just turned 14, a couple of days later, Tony came up to me and said 'you've just broken a world record'."

"Before I knew it, I went to Adelaide [for trials] and I was selected for Tokyo." for more details on Elizabeth's story:





https://www.abc.net.au/news/2019-08-25/when-elizabeth-edmondson-made-history-at-1964-tokyo-paralympics/11431100

Elizabeth also attended our SA Retreat at Glenelg and also attended our 2013 lobbying trip to Canberra .

https://www.stillhere.org.au/elizabeth-edmondson/

https://www.stillhere.org.au/fight-on-polio-plight/

Esther Simbi — My Polio Story

I was born in Kajo-Keji South Sudan to a peasant family. I don't know what year I was born. It was a home birth in the village with no birth certificate, so my mother didn't remember the year I was born. The year of birth in my visa to Australia is 1977. I don't look or feel 41 years old, so I calculated and guessed my age to a more realistic age which is 37 years. Unfortunately, I have not been able to change my age to the more realistic one here in Australia because I don't have a Birth certificate to prove my age. If I was four when I contracted poliomyelitis, then I am 37 years old now but not 41. My father was a primary school teacher in 'Beliyak Primary School in Kajo-Keji South Sudan, and he also worked as a cleaner in Mundari Hospital in Kajo-Keji South Sudan. My mother didn't have the opportunity to pursue education due to the South Sudanese cultural practices where women are trained to be housewives, mothers and family/community carers. My parents were divorce when I was four years old and my mother went to live with her relatives in a village called Lomura leaving me and my siblings with my father. In the South Sudanese culture, children belong to their father. In any case of marriage, relationship or family breakdown the woman will leave

without her children and that was what my mother did. A few months later, my three sisters and I were reunited with our mother after our father took ill and was unable to look after us. I am the youngest of six children and I am from the South Sudanese Kuku community. I speak the Kuku language and English. A few weeks after settling in my mother's village Lomura, I contracted poliomyelitis. One morning in Lomura

Village South Sudan, I woke up with a high fever and a body paralysed from neck to toe. I was not able to stand or sit up. My mother gave me a medicine made from local herbs, and she invented her own form of physiotherapy treatment where she massaged my body in cold water every morning. She also tied my hands to two poles to support me, and she left me to stand there for an hour every morning and evening for two to three months. I had to learn to sit and to walk again, and I eventually regained strength in my upper body. Thanks to my mother, who worked tirelessly, I was able to walk again, though with great difficulty.

There was no immunisation available in South Sudan when I was born to immunise children against polio. I was left with a weak lower back, a deformed and painful right foot, and a very weak left leg. My left leg is 2 inches shorter than my right leg which makes balancing difficult when walking. I bend forward when walking, putting a lot of strain and pain on my lower back. I now suffer from post-polio syndrome, which is associated with headaches, muscle, bone and joint pain, fatigue, and general body exhaustion. I limp and have a lot of falls causing injuries. In December 2015 when I was pregnant with my now 3-year-old daughter, I had a fall and fractured my left ankle. Wearing a plaster for 6 weeks meant that I had to learn to walk again as the plaster had weakened my left leg muscles even more. I am on a waiting

list for surgery to fix my right knee. I am on medication to manage the pain in my right knee. I use a wheelchair outside of the house to access the community. I try not to use the wheelchair much to keep my muscles strong and active. I use my left arm to push my left knee back when I am walking for balance to aid my mobility. I have damaged my left elbow because of the way I walk and now I am waiting for surgery to fix my elbow. When I was young, my legs muscles were stronger and I was able to walk for 10 to 15 minutes without resting but after I turned 25 years old here in Australia, my muscles started to weaken. Now I cannot walk for five minutes without resting and falling. My sight in my left eye is weaker than the sight in my right eye. I also choke while swallowing. I now see a speech pathologist funded by NDIS to manage my swallowing. I was diagnosed with late effects of polio called Post-Polio Syndrome here in Australia 13 years ago.

In 1987, my family and I fled the Sudan civil war and resettled in Uganda where I grew up in three different refugee camps for 19 years before migrating to Australia. I migrated to Australia in July 2005 as a refugee where I completed a bachelor's degree in social work in 2007 and a

master's degree in Mediation and Conflict Resolution in 2014 at the University of South Australia. I am a single mother of two beautiful daughters aged 8 and 3 years old. I worked with Families SA and Disability SA from December 2007 to July 2013 as a social worker, Case Manager, Service Coordinator, Intake Coordinator and as a Facilitator. I was also the Founder of, and the Coordinator for, the Crossing the Bridge Project in 2014 which was aimed at

supporting African Women with Disabilities in South Australia, and supporting mothers of African children with disabilities as wells wives and female family members of African men with disabilities in South Australia. I ran for Parliament with Dignity Party SA (formerly known as Dignity for Disability) in the Upper House as a Lead candidate for the South Australia's State Election in 2014 and I was also on the Dignity Party's Upper House ticket for the 2018 South Australia's State Election, representing people with disabilities in South Australia. I was the first African Woman from a refugee background to run for Parliament in Australia.

In March 2019, I published my first book Beyond Calamity which is the story of my life journey, contracting polio in South Sudan as a 4 year old girl and surviving that, growing up in 3 different refugee camps in Uganda, growing up and overcoming challenges as a girl and as a woman with a disability in the South Sudanese Community, migrating to Australia as a refugee 14 years ago and overcoming challenges on a daily basis as a single mother and as a woman with a disability. My book is available on the publisher's website Vividpublishing.com.au/beyondcalamity and it's \$30.

Please see details to purchase Esther's Book on next page and after reading Esther's Book if you could leave an online review it would be appreciated.

Beyond Calamity — Polio Survivor

A South Sudanese refugee's story

Author—Esther Simbi

My Journey from Disability and Disaster — to Possibility and Empowerment

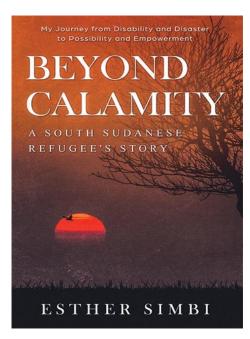
From writing sums in the dirt with her finger at a poor village school in South Sudan, Esther Simbi rises above disability to become a Social Worker and Disability and Human Rights advocate in Australia.

Giving voice to the voiceless is her passion. She believes that disability is not inability, age is just a number, and 'refugee' is just a label.

From polio at age four, through nineteen years in refugee camps in Uganda, Esther's stories of life in South Sudan and as a refugee will move, shock and inspire you..

About the Author





Esther Simbi is living proof that disability and disadvantage need not define us. She has overcome incredible odds: losing health, family, home, and community; surviving rape; and living as a refugee for nineteen years. She was the first African woman from a refugee background to run for parliament in South Australia, where she represented people with disabilities. Education, she believes, is the key to empowerment, and she works tirelessly to empower those who do not have a voice, or have not yet found their voice, to lessen inequality and disadvantage.

Vivid Publishing ACN 124 367 086 ABN 91516 588 690

To Purchase Esther's Book go to link below

http://www.vividpublishing.com.au/beyondcalamity/

PAPERBACK EDITION

\$21.95 + \$8.50 P&P.

Australian delivery

Esther's book is also available on Amazon and on Booktopia. Online reviews on Amazon, Booktopia and on Goodreads.

Polio Australia Health & Wellness Retreat

ninth and final retreat







Polio Australia's ninth and *final* Polio Health and Wellness Retreat. The retreat focuses on 'Body, Mind & Spirit", encompassing a range of selfmanagement strategies for polio survivors and their carers.

Date: Thursday 17th October – Sunday 20th October 2019

Location: St Joseph's Centre for Reflective Living, 33 Barina Downs Rd, Baulkham Hills, NSW 2153

Cost: \$400 per person or \$350 per person twin share/double rate

Contact Polio Australia

Ph: 03 9016 7678

Email:

office@polioaustralia.org.au

St Joseph's Centre for Reflective Living is a lovely, peaceful environment, and very conducive to sharing and learning new information. The venue is approximately 30 minutes north-west of Sydney CBD and approximately one hour from Sydney Airport.

St Joseph's is a wheelchair accessible venue with elevators to the upstairs accommodation. All rooms booked for this Retreat have walk-in showers. If requested, Polio Australia will hire shower stools, and over the toilet risers to help make the bathrooms more accessible and ensure your safety. This equipment will need to be booked in advance

Additional Information:

- Single, double, and twin room configuration is available.
- There is a shared 'bath room' on each of the two accommodation floors for those who prefer a bath .
- All rooms have air-conditioning, internet and telephone services.
- There are several guest lounges with kitchenettes, as well as TV/DVD lounges on each level for guest use. There are no TV's, fridges or tea/coffee facilities in the rooms.
- There is a computer room on level one with two computers for guest use.

https://www.polioaustralia.org.au/retreat-2019/

Polio SA Inc The Post Polio Support Group 302 South Rd Hilton SA 5033



Subscription Renewal Form (due on July 1 st for 2019/20 membership)
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Humor

Just for laughs

THERE were two nuns.

One of them was known as Sister Mathematical (SM), and the other one was known as Sister Logical (SL). It is getting dark and they are still far away from the convent. SM: Have you noticed that a man has been following us for the past 38 1/2 minutes? I wonder what he wants. SL: It's logical. He wants to violate us. SM: Oh, no! At this rate he will reach us in 15 minutes at the most! What can we do? SL: The only logical thing to do of course is to walk faster. A little while later... SM: It's not working. SL: Of course it's not working. The man did the only logical thing. He started to walk faster, too. SM: So, what shall we do? At this rate he will reach us in 1 minute. SL: The only logical thing we can do is split. You go that way and I'll go this way. He cannot follow us both. So the man decided to follow Sister Logical. Sister Mathematical arrives at the convent and is worried about what has happened to Sister Logical. Then Sister Logical arrives. SM: Sister Logical! Thank God you are here! Tell me what happened! SL: The only logical thing happened. The man couldn't follow us both, so he followed me SM: Yes, yes! But what happened then? SL: The only logical thing happened. I started to run as fast as I could and he started to run as fast as he could. SM: And? SL: The only logical thing happened. He reached me. SM: Oh, dear! What did you do? SL: The only logical thing to do. I lifted my dress up. SM: Oh, Sister! What did the man do? SL: The only logical thing to do. He pulled down his pants. SM: Oh, no! What happened then? SL: Isn't it logical, Sister? A nun with her dress up can run faster than a man with his pants down. And for those of you who thought it would be dirty...... Say two Hail Marys!!!



Newsletter contributions

Do you have a story to share? Write a letter to the editor. Articles can be sent to us via email or post.



poliosa.office@gmail.com



To the editor, Polio SA, 302 South Road, Hilton SA 5033

Articles for the next issue are due to the editor by the end of Oct.

Polio SA Inc office

We love hearing from our members. Whether you have post-polio symptoms or if you require information, call us on:



0466 893 402

Please keep in mind that our office hours are currently unpredictable. If you wish to visit our office, please telephone ahead. Our office phone is redirected to a committee member.



Dr Nigel Quadros

Queen Elizabeth Hospital Level 8b. Woodville Road **Woodville SA 5011** Phone: 8222 7322

nigel.quadros@health.sa.gov.au

Dr Nigel is Director of Rehabilitation Services at the Queen Elizabeth Hospital and St Margaret's Rehabilitation Hospital and also a Senior Clinical Lecturer at the University of Adelaide Healthcare. He is a Fellow of the AFRM (RACP). His areas of interest include stroke and general neurological rehabilitation, amputee rehabilitation, pain management, management of post-polio syndrome, and Continuing Professional Development.

A referral from your local GP is required for appointments. Dr Quadros can arrange assessment by their physiotherapist and orthotic department and any tests as required. If you have any specific questions you can email him directly.

When visiting Dr Nigel, take the lift to the 8th floor in the main building and follow the signage for 8b.

Member Services

If you are interested in any of these services ring our office on 0466 893 402 and ask for vouchers.

There is a limit of 4 vouchers per person with a maximum value of \$40 per person.

Remember you must be a paid up member to receive vouchers.

City

PhysioXtra

115-117 Pirie Street, Adelaide SA 5000 Phone: (08) 7221 9110

Eastern suburbs and Hills

TOORAK GARDENS

The Physio Clinic

Godfree House, 2 Moore St, Toorak Gardens SA 5065 Phone: (08) 8342 1233

NORWOOD PhysioXtra

Suite 1/39 Clarke Street, Norwood SA 5067 Phone: (08) 7221 9289

PhysioXtra

110 Magill Road, Norwood SA 5067 Phone: (08) 8132 1266

NAIRNE John Kirkwood Polio Practitioner

19 Federation Way, Nairne SA 5252 Phone: 0410 779 159

Northern suburbs

PROSPECT The Physio Clinic

177 Prospect Road Prospect SA 5082 Phone: (08) 8342 1233

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Phone: 0430 867 248

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MARION

PhysioXtra

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UNLEY Unley Medical Centre Unley Physiotherapy

160 Unley Road, Unley SA 5061 Phone: (08) 8373 2132 Car parking off Mary Street is accessible. Facilities include a disabled toilet and wheelchair access.

WOODCROFT Bruce Harrison

14 New England Drive Woodcroft SA 5162 Mobile: 0402 337 382

bruce_harrison@aapt.net.au

Western suburbs

HENLEY BEACH

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506 Henley Beach Road Fulham SA 5024 Phone: (08) 8356 1000

WOODVILLE SOUTH

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Outer metro

GAWLER Physio-Wise

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3 Murray Street, Gawler South Australia 5118

LYNDOCH

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48 Altona Rd Lyndoch SA 5351

Regional

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STREAKY BAY Tahlia Gosling

Remedial Massage

19 Alfred Terrace, Streaky Bay SA 5680 Phone 0427 394 948

Change of address

If you have changed your address recently, please fill out the following and mail to the office at:

Secretary Polio SA 302 South Road, Hilton SA 5033

Please supply your email address I f you would like to join our database and receive email newsletters in future.

New details

Old details	Name
Name	Street
Street	Suburb/Town
Suburb/Town	Postcode
Postcode	Phone number
Phone number	Email
Email	



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