

# *Quarterly* NEWSLETTER

# Welcome to the Winter Edition of the Polio SA Newsletter

#### Greetings!

Again, I write as our president is still in recovery mode, and we do wish him all the best. Well, much, and nothing, has happened since our last newsletter! As you are aware, our state government funding comes to an end as of June 30. This funding has enabled Polio SA to provide you with all the support you have become accustomed to.



On a positive note, we will be staying at South Road. We will be in a sub-lease arrangement with SACID. The actual rent will be much less, but there will be some expenses like insurance which we will now have to pay.

Since before Christmas, Helen and I have been busy writing letters, and in some cases, getting a response! Some letters have culminated in an actual visit to those in power to help us source some funding to continue providing for you. In most cases the pollies were genuinely concerned.....but to be brutally honest, that's where it stopped. Some non-responders include Bill Shorten [now Federal shadow Minister for Disability], Stephen Wade [our Minister for Health]. Our own Minister Lensink still refuses to meet with us relying on advice from her "advisers", who erroneously continue to believe either My Aged Care, or the NDIS are for us, albeit despite the evidence which says that both systems are woefully underfunded.

So, friends, at the time of writing, things don't look good. However, we still have a "couple of irons in the fire ". Ms Rebekah Sharkie Federal Member for Mayo is prepared to advocate on our behalf, and in June I have a meeting with Mr Mark Butler, the Federal shadow Health Minister.

In the meantime, Helen has let you know about Angela Duigan at Disability Advocacy. They are currently collecting and collating personal stories of people living with disability. But wait! There's more! They are prepared to visit you, to take your story. Do avail yourself of this offer.

If you haven't already, contact your local M.P. Ask them......

- 1. What do you know about living with Post-Polio?
- 2. What have you done to secure on going funding for Polio SA?
- 3. What will you do to get ongoing funding?

BUT.....don't accept the glib reply of "I'll write to the minister" ...... she doesn't respond to us! And don't forget, give them a couple of weeks, and then ring again and ask for an update.....

Also, in the previous newsletter, with tongue slightly in cheek, I put it about that we could do with a benefactor. I now no longer have tongue in cheek! Finally, I would like to take the opportunity to thank Helen for all her efforts over the past months in our quest for funding.....she has been a terrific help, and then some! And can members please be mindful that Helen is our paid staff...... she is only paid for two days a week [but puts in a lot more]. We need therefore to factor in that those days are Mondays and Thursdays. Until the AGM, stay safe, stay well.

DON'T FORGET!!!! Nominate to get on the committee, and/ or to take up a role in the organization.

<sup>ed simply</sup> views or Vice President Polio SA.

Issue 142 Winter 2021

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# Polio SA

The post-polio support group for South Australians

0466 893 402

poliosa.office@gmail.com

302 South Road, Hilton SA 5033

www.poliosa.org.au

poliosouthaustralia

Disclaimer: Polio SA Inc. assumes no responsibility for any treatment undertaken by readers of this newsletter. Any advice, either explicit, or implied is not intended to replace qualified medical advice.

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.

Polio SA Inc. does not express or imply endorsement of physicians, products, seminars or services that are mentioned in this newsletter. They are mentioned simply as a public service to polio survivors and those interested in them. Articles do not necessarily reflect the views or policy of Polio SA Inc.

# ATFA in Conversation with Graeme Innes

Improving access to assistive technology for people outside the NDIS



We're hearing a lot about the shortcomings of the NDIS and the threat of independent assessments. While these are important issues, what about the 90% of Australians with disability who are not eligible for the NDIS at all?

# The **Assistive Technology for** <u>All Alliance</u> is advocating for a universal assistive technology program to meet the needs of people with disability who are excluded from the NDIS.

Come along to our **free online forum** featuring former Disability Discrimination Commissioner, **Graeme Innes AM**, to find out more.

# During this event, you will:

- Learn more about Australia's obligation to provide assistive technology to people who need it
- Hear from people with disability who are directly affected by the lack of access to assistive technology outside the NDIS
- Learn more about the Assistive Technology for All campaign and how you can get involved.

This event will be Auslan interpreted.

**Get in touch:** call COTA Victoria on 1300 13 50 90 if you have queries or need assistance with booking.

Date: Wednesday 9 June 2021 Time: 11 am - 12.30 pm | Location: Zoom

**Register online** 



# Save the date — Annual General Meeting

All members are warmly invited to attend this year's Polio SA Annual General Meeting When: 1pm, Sunday 19th September 2021 Location: Thebarton Community Centre Cnr South Rd & Ashwin Parade ,Torrensville South SA 5031

# COMMITTEE NOMINATION FORM

POLIO S.A. Inc. ANNUAL GENERAL MEETING 19th September 2021				
This form is to be sent to: The SECRETARY, Polio SA, 302 South Rd Hilton SA 5033				
I (Members Name)				
Hereby Nominate:				
If you nominate another person then that person must also sign to acknowledge and agree to the nomination.				
President		Vice President		
Secretary		Treasurer		
Committee Member (8 max.)			DON'A DRGK	
Signed				
Nominations for Committee positions must be lodged with the Secretary not later than 22nd <sup>t</sup> August 2021				

DHS conducted a survey of Polio SA members to determine how many members would require assistance to transition to the National Disability Insurance Scheme or My Aged Care services. Sixty-eight members responded, and of these members, forty three advised that they are already clients of My Aged Care. These results are shown in the table below.

Summary of Survey Responses (April 2021)

SUMMARY OF RESPONSES	Number of Members
Responses:	68
My Aged Care Clients	43
Not engaged with My Aged Care	23
My Aged Care Client—don't know	1
National Disability Insurance Scheme client	1
Average age (n=68)	78
Average age of My Aged Care clients (n=43)	78
MEMBERS RECEIVING SERVICES FROM POLIO SA	
No services / 1 does not want to participate	6
Allied Health Services	35
Social Support	26
Information and Advocacy	48
My Aged Care clients receiving Allied Health Service via Polio SA	22
Non-My Aged Care Clients receiving Allied Health Services	13

note that thirty-five My Aged Care clients are receiving allied health services through Polio SA. I encourage you to ask your members to explore whether they can receive these services via My Aged Care when their service plans are next reviewed. For example, podiatry, occupational therapy and physiotherapy can be included in a person's Home Care Package.

I have met with representatives from the Commonwealth Department of Health to discuss access to My Aged Care for your members. As the number is smaller than expected they have recommended that your members utilise the standard access processes with assistance from their GP, from The Catalyst Foundation or from the Council on the Ageing.

The Council on the Ageing has three different programs which help you to get independent support and information around accessing and engaging with My Aged Care services. They also have an Aged Care Specialist Support Worker, Julie Lawrie, for the Metropolitan area, who can assist people to link into My Aged Care and provide advice about resources available to older people.

Julie can be contacted on telephone 0484 143 772 or 1800 182 324. Other dedicated support workers are also available for regional areas of South Australia and can be found at https://www.cotasa.org.au/programs/my-aged-care-support.aspx

The Catalyst Foundation can also provide support to your members to navigate My Aged Care or the National Disability Insurance Scheme and can be contacted on telephone (08) 8168 8776. Their website provides an Aged Care Guide and can be found at https://www.agedcareguide.com.au/catalystfoundation.

(letter received from Dept of Human Services to Polio SA 29/04/2021 in relation to survey asked of Polio SA Members by DHS)

Polio SA Members,

We wanted to provide some information from our recent Committee meeting.

We had a representative from The Disability Rights Advocacy Service Inc attend her name is Angela Duigan. They would like to collaborate with us in providing them with individual submissions to the Disability Royal Commission. We thought it would be very important to get our voices heard. Angela and the Committee feels especially for us in the category of neglect i.e.: Discrimination not being able to access NDIS scheme. Also, not enough Allied Health Support within the aged care system to support our members in regard to post-polio syndrome etc.

Polio SA Committee.

Disability Rights Advocacy Service Inc

PO Box 742

Torrensville SA 5031.



Dear Polio SA Members

We write to advise you about how the Disability Rights Advocacy Service can support people to tell their stories to the **Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability** ("Disability Royal Commission").

The Disability Royal Commission wants to hear from people with disability, their families, carers, and other community members about their experiences of violence, abuse, neglect, or exploitation.

Our advocates provide a free and confidential service and will assist people to prepare their submission in the way that they are most comfortable with – in writing, recording their voice or by recording a video. We can also assist and support people who wish to participate in a private session with a Disability Royal Commission Member.

Our advocates can also help people to access other supports such as interpreters and can connect people to services such as free legal and counselling services.

We would be most keen to talk in more detail about the Disability Royal Commission to you if at all possible.

Please contact me **Angela** on **M: 0410 056 681** to arrange a time for us to meet. We are also able to organise free interpretation services if required.

Disability Rights Advocacy Service's advocates are also available to advocate for people with disability in matters including issues they might have with access, Centrelink, the NDIS, Guardianship and Administration, disability discrimination and any other issue that might impact on them.

We are also back to no restrictions on home / face-to-face meetings. We also can meet with people at our Kent Town office – Base 64, 64 North Terrace, Kent Town.

We look forward to hearing from you soon.

Yours sincerely

Angela Duigan Disability Royal Commission Advocacy Officer <u>aduigan@dras.com.au</u> 0410 056 081 Website dras.com.au

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Polio SA Inc	$\sim$
The Post-Polio Support Group	
302 South Rd	Polio S
Hilton SA 5033 Tel : 0466 893 402	FOID S
poliosa.office@gmail.com	
<b>Subscription Renewal Form</b>	(due on July 1 <sup>st</sup> for 2021/22 membership)
Annual Subscription	
\$20 Individual Member	
\$25 Member and Carer	
\$25 Organisation	
ORGANISATION (if applicable):	
SURNAME (Dr / Mr / Mrs / Ms / M	iss)
GIVEN NAME:	
ADDRESS:	
POSTCODE EM	AIL
PHONE No	MOBILE No
Please sign below to meet Government Priv	acy Act Requirement
I consent to Polio SA Inc. retaining the abo	ve details until I cease to be a member of this group
Signature Required	
<u>Methods to</u>	Pay Subscriptions
Personal cheque made out to Polio SA	Inc. to accompany this form.
Postal order made out to Polio SA Inc.	to accompany this form.
Bank Transfer at your local branch or c	on the internet (subscription form must still be returned)
BSB Number: 105-084	
Account Number: 326443840	

Post this form to: Polio SA, 302 South Rd, HILTON SA 5033 or email to poliosa.office@gmail.com

(Sorry plastic no longer accepted)

I have enclosed a donation of

I have enclosed a subscription of \$.....

Description: Polio SA + Surname

(No receipt will be issued unless requested

and self stamped addressed envelope enclosed.)

\$.....

N Sa

# Steroids or Ibuprofen warning some info from one of our members.

Hi fellow PPS sufferers.

A few weeks ago, I unfortunately picked up a nasty and persistent bug with the usual runny nose and annoying cough and apart from the standard cold and Flu drugs I was finding it difficult to throw off the cough so resorted to a very good drug called Breo Elipta 100/25 mgc which is a steroid inhaler that I was given after suffering a collapsed lung a few years back.

Foolishly I became a bit impatient as it was not working as quickly as I expected so had a visit with my local doctor to ask him to prescribe me the stronger version Breo Elipta 200/25 mgc as I was running low on my last low dose pack.

I was most appreciative of the fact my doctor gave me a script which allowed me to buy it on the cheap and not to have to take out a bank loan as it is very expensive.

Problem was I tried a puff of the 200MCG that night and certainly slept well but felt absolutely crappy next day it was way too strong for me and I had all the classic symptoms of a reaction to the Steroids which was quite frightening so skipped it for a day and then went back to the 100/25 dispenser.

The next day which happened to be the bad dust storm we had in April and by that night I was still feeling very unwell but to digress a little here as well as PPS I also suffer from Hydrocephalus and was worrying that my shunt was playing up so went back to the doctor to get a referral for a brain scan fearing a third lot of brain surgery.

I had the scan which proved negative so was much relieved but by that night I still felt just awful so in despair at about 5.30 pm resorted to Doctor Google and asked the question "Should PPS sufferers use Steroids" well back came the answer, to my shock and horror the reply came back saying that Post-Polio people should definitely avoid the ingestion of both Steroids or Ibuprofen at all costs as it reacts badly with our insulin and sugar levels so I immediately rang a friend of mine who is a diabetic and asked him if I could come over and check my blood sugar level. I was okay in that department.

What I experienced was very high stress levels if the slightest thing went wrong.

The article I found on the net came from a book written by a doctor named Richard Bruno and I placed an order for it straight away it is called the Polio Paradox. His article is an important must read.

I know polio victims are a small dwindling group of our society so very few doctors know much about it but I figured if I took the time to write this up and it prevents someone from going through some unnecessary grief in the future so be it, I asked my doctor for the stronger version of the Breo Elipta so it was really my problem.

Regards Rodney Muller 22nd April 2021

https://www.papolionetwork.org/uploads/2/7/7/2/27726699/ my\_doctor\_prescribed\_steroids\_by\_dick\_bruno.pdf

Thankyou Rod for sending in this information.



# **Brett Howard Celebration of Life**

We wanted to pay our respects to Brett , his family and friends are holding a

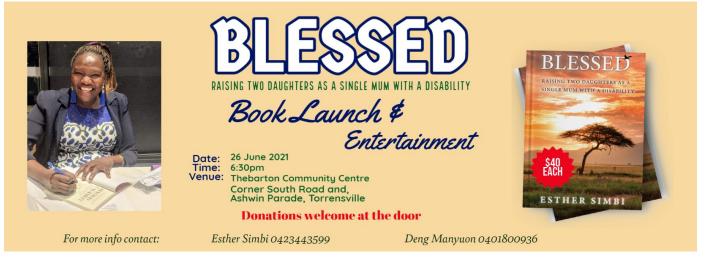
Celebration of life event on the 5th June 2021 at The Adelaide Speedboat Club which was Brett's second home according to son Chad.

This will be one year on from Brett's passing he is dearly missed.

We remember Brett and the amazing work he did as our President for over 10 years. Brett's family will honor him and spread his ashes at the river, which Brett had requested.

Thinking of you all on this day and many thanks to Brett for all he did for Polio SA

# Polio SA member Esther Simbi has kindly invited members to her book launch on the 26th June 2021



Esther asked that if you need any more details you are welcome to contact Esther directly on 0423443599 for more information or if anyone would like to make a donation before the event. We thankyou Esther for your kind invitation and look forward to reading your book Blessed we really enjoyed reading your previous book Beyond Calamity and recommend to all.

Please contact the Polio SA office on 0466 893 402 if you would like a copy of below publications.







# **Updates from Polio Australia**

National polio survivor education:

VERY EXCITING NEWS! \$400,000 has been allocated to Polio Australia's community programs over the next four years. We're very happy to have the opportunity to continue to facilitate learning and sharing among the polio community.

**Community Information Sessions:** 

Our monthly Zoom chats continue to be well-attended, with around 30 in April and 25 in May.

On Wednesday 5th May we had a webinar on self-advocacy, with Liz Telford. We had more than 30 people attending, and it was a great presentation and discussion. It will likely lead to more

Our next NDIS-themed chat will be Wednesday 16th June, at 11am AEST.

Information and booking links for all sessions are at www.polioaustralia.org.au/

community-information-sessions

# <u>Advocacy</u>

Equal access to Assistive Technology-ONLINE FORUM 9TH JUNE

The Assistive Technology for All Alliance (ATFA) is hosting an online forum with

Graeme Innes (noted disability advocate and former Disability Discrimination Commissioner) on the 9th of June, 10.30 am SA). This event will raise awareness of the inequalities facing older people with disability (and anyone with disability outside the NDIS).

(Details are on page 2 of this newsletter)



Polio SA Membership subscriptions due 1st July 2021.

Please see page 6 for subscription form.

Thankyou for your ongoing support.

# **Room For Thought**

- Did you hear about the mathematician who's afraid of negative numbers ? He will stop at nothing to avoid them
- Why did Beethoven get rid of his chickens ? All they said was Bach, Bach, Bach.
- Heard about that new band called 1023
  MB?

They haven't got any gigs yet.

• Why were they called the Dark Ages ? Because there were lots of knights



- How does NASA organize a party? They Planet
- What did the nose say to the finger? Quit picking on me
- What did the left eye say to the right eye ?
   Between me and you something smells
- Why did the M&M go to school? He wanted to be a smartie
- Why do bees have sticky hair? Because they use honeycombs

# 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 31st August 2021

# Polio SA Inc office

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



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 our services ring office 0466 893 402 and ask for vouchers There is a limit of 4 vouchers per person with a maximum vale of \$40 per voucher. 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) 8331 7586

#### NAIRNE

John Kirkwood **Polio Practitioner** 

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

# Northern suburbs

ELIZABETH **Richard Barker Physio** 

2 Burgate St Elizabeth Grove SA 5112 & 3 Tolmer Rd Elizabeth Park Phone:0438826517 (state from Polio SA when booking)

# **ROYSTON PARK**

**Magic Hands Massage** Centre – Carrol Morgan Sports & Remedial Massage, Reiki, Aromatherapy, Foot Reflexology, Neuralign

254 Payneham Road, Royston Park SA 5070 Mobile: 0409 097 080 Phone: (08) 8390 1206

## **GOLDEN GROVE**

**Golden Grove Family** Health – Diane Preston Massage Therapist 205 The Golden Way, Golden Grove SA 5125 Phone: (08) 8289 1222 Fax: (08) 8289 1255

## **NORTH EASTERN SUBURBS**

#### **Mobile Massage**

This can only be done on certain days and takes around 3-4 clients a day.

Preference given to house bound and the more handicapped person.

Arrangements to be made with Reeva Brice Phone: (08) 7423 7162 Mobile: 0412 866 096

PARALOWIE Wax on wax off by Gen 10 Airdrie Ave Parafield Gardens SA 5107 Phone: 0430 867 248

# HALLETT COVE

Southern suburbs

PhysioXtra

1/1 Zwerner Drive, Hallett Cove SA 5158 Phone: (08) 8387 2155

# MARION

PhysioXtra

724 Marion Road, Marion SA 5043 Phone: (08) 8357 4988

## **MORPHETT VALE**

#### Hands on Health Massage – Jimmy Kucera

Shop 7, 20 Taylors Ave, Morphett Vale SA 5162 Phone: (08) 8325 3377 Plenty of car parking. Flexible times.

# REYNELLA

# South Side Health Care

Noarlunga Aquatic Centre Complex, Reynella SA 5161 Phone: (08) 8382 2255

# UNLEY **Unley Medical Centre** Unley Physiotherapy

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

**Physio-Wise** 

## Regional

**PhysioXtra** 39 North Terrace, Port Elliot SA 5212 Phone: (08) 8554 2530

**STREAKY BAY** Tahlia Gosling **Remedial Massage** 19 Alfred Terrace,

Streaky Bay SA 5680

Western suburbs

# HENLEY BEACH Massage Therapist, **Pilates & Physiotherapy**

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

## SEMAPHORE

**Bruce Harrison** 100 Semaphore Road Semaphore SA 5019 Mobile: 0402 337 382 bruce harrison@aapt.net.au

### WOODVILLE SOUTH

The Physio Clinic 2/95 Findon Road Woodville South SA 5011 Phone: (08) 8342 1233

# Outer metro

## GAWLER

Physio-Wise Phone: (08) 8522 6611 Australian Physiotherapy Association Member

### LYNDOCH

Phone: (08) 8524 5094 Australian Physiotherapy Association Member

# PORT ELLIOT

# 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.

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

Name

New details

**Old details** 



If unclaimed, please return to:

Secretary Polio SA 302 South Road, Hilton SA 5033 AFFIX STAMP HERE

# Please send all mail to:

Secretary Polio SA 302 South Road, Hilton SA 5033