



POLIO NSW

Supporting polio survivors and their families since 1989

Formerly Post-Polio Network (NSW)

Polio NSW is a member of Polio Australia

Website: www.polionsw.org.au

President: Gillian Thomas OAM
Vice-President: Susan Ellis
Secretary: Merle Thompson OAM
Treasurer: Alan Cameron

PO Box 2799 North Parramatta NSW 1750
Phone: 02 9890 0946
Phone: 02 9890 0953
Email: office@polionsw.org.au

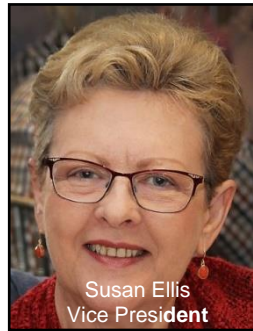
Patrons: Michael Lynch AO CBE

Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

2022 - 2023 ANNUAL REPORT



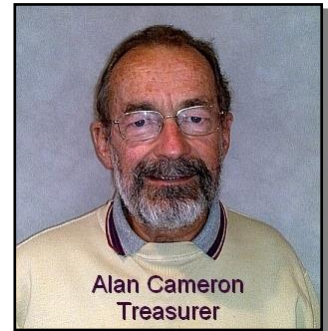
Gillian Thomas
President



Susan Ellis
Vice President



Merle Thompson
Secretary



Alan Cameron
Treasurer



Ella Gaffney
Support Group Coordinator



Gail Hassall



Geraldine James



Rosalie Kennedy



Vasa Marimuthu



Bill McKee



Diana O'Reilly



Esther Smart

Polio NSW 2022/2023 Board

From the President

Gillian Thomas

At our 2022 Annual General Meeting we were delighted to appoint a full contingent of Board members, combining old hands with fresh ideas. Together with its governance responsibilities, the Board's continued focus this year has been on engaging with as many members as possible through printed newsletters, regular email news updates, video webinars, and in-person and online support groups. Reports on our activities in pursuit of this engagement follow in this, our 34th Annual Report. My thanks go to all Board members, in particular Sue, Merle, Gail, Rosalie and Ella, who made it possible to accomplish these activities. Thanks are also due to our Treasurer, Alan, whose careful management of our finances ensured we finished the year in a healthy condition.

As others have written, in December we farewelled George as Office Co-ordinator. After 18 dedicated years in the role, he had certainly earned his retirement and the chance to take life a bit easier. George hasn't been totally lost to us, though, as he still helps out with mailouts. Fatma still works in the Office one day a week, and is rapidly approaching her 15th anniversary with Polio NSW.

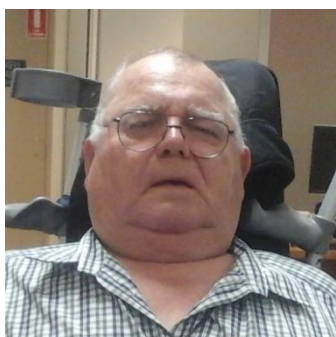
Social Sector Transformation Fund Project

Merle Thompson, Secretary

The grant which Polio NSW obtained under this NSW Government program was due to be completed on 30 June 2022. Organisations which had not fully expended their funds were able to have an extension until the end of the year. Polio NSW took advantage of this extension and continued to employ Gail and Rosalie for the extra period. This enabled us to hold additional webinars and to continue the online support group including initiating the Human Library program.

Polio NSW Office

Fatma Alameddine, Admin Officer



George Laszuk (retired Dec 2022)



Fatma Alameddine

The beginning of the financial year started without John Doyle who resigned in June 2022 due to ill-health. We hope that he is doing well.

Within the first part of the year, July to December, George and I carried on with the work in the office; I changed my work day to Mondays as I was working on Thursdays originally. Then a few months later I started working Tuesdays.

Our tasks were mainly George picking up the mail, with us both updating the membership database, answering phone calls, emails and other correspondence when required. We also organised mail outs when needed which required the processing of mail sheets and renewal forms. The updating of various databases was also performed when required including statistics databases as well as checking emails and distributing information kits to new members.

In addition I was also simultaneously working on MYOB our computer financial system which included the processing of payments of membership renewals and donations and the generation of receipts for these payments. I also processed the payment of invoices.

We had a number of mail outs – membership renewal forms, *Network News* newsletters and the AGM 2022 reports and notification of AGM meeting.

We also found out that George would be retiring after 18 years working as Office Co-ordinator for Polio NSW and would not be working in the office anymore. We were sad to see our friend leave and we thank him for all his hard work and dedication working with us for Polio NSW as our trusted colleague. We wish him and his family well in their future endeavours. We then broke for the Christmas break and holidays. In May 2023 a farewell lunch was put together by our hard-working office volunteer Di O'Reilly and those who attended had a great time wishing George well and telling stories of his time in the office. It was especially lovely to see John Doyle attend George's lunch.

I took January off for my annual leave and returned to the office, once again changing my work day to Wednesdays in order to work alongside Shylie Little in the office doing all the tasks mentioned above. At first we had a few setbacks working now with laptops and new MYOB processes, but slowly and surely I am getting used to it. The new MYOB system has streamlined the workload.

We have had 2 mail outs since January (latest newsletter for March and June for our annual membership renewals) with the help of George who came in as a volunteer.

Network News

Susan Ellis, Editor

The year under review, July 2022 to June 2023, has seen Polio NSW Board members refine their skills with the new technology such as Zoom and the internet, as it seeks to engage members, many of whom are unable to physically participate in face to face meetings and seminars.

This technology has had an impact on the content of *Network News* in that we are committed to reporting the increasing number of webinars available to members in order for those members who have no access to a computer are not deprived of the information available via the webinars.

Three newsletters were published and distributed this financial year. The following is a summary of the content of each newsletter.

Network News: Issue 115, September 2022

After Stephanie Cantrill's resignation two board members took over the positions of online support group convenor (Rosalie Kennedy) and host of online webinars (Gail Hassall). In this issue of *Network News* Gail reports on those seminars that have taken place to date and what has been booked for future dates.

Rosalie Kennedy reported on the progress of the monthly online support group – **Polio Human Library – Our Human Books – Living our Polio Lives – Our Way**. With each session Gail and Rosalie, as well as the presenters, have honed their zoom meeting skills.

In this issue there is an extensive report on the July webinar on **Nutrition** presented by Melinda Overall, Nutritionist and Counsellor. Melinda offered information about energy and fatigue, weight management, muscle tone and inflammation and examples of the best foods to choose for dealing with these issues. There was also information on age-related digestive changes, suggestions on healthier food swaps, short cuts for making a healthy choice when energy to prepare a meal is low and helpful tips and recipes.

Dr Marny Eulberg's article on itching and skin care covers the scenarios of dry skin or a rash with different treatments and advice for each. The article also addresses the issue of pressure sores and the various stages of these sores. Specialised cushioning for beds and wheelchair seating as a management tool are suggested.

Dr Richard Bruno covers the topic of Neuropathy – damage to a neuron which can cause numbness, pain, burning, tingling and sometimes muscle weakness in the arms, hands, legs and feet. Damage to neurons can also be caused by the overuse of muscles eg in wrists (carpal tunnel syndrome) from the use of crutches or walking sticks. Dr Bruno also lists other common causes of peripheral neuropathy such as diabetes.

Network News: Issue 116, February 2023

This Newsletter reported on the results of the 2022 AGM which included the election of two new members Geraldine James and Esther Smart. Nola Buck did not stand for re-election, her commitment and support to the board over decades, including the position of President, has been impressive and appreciated and significant to the success of Polio NSW. Shirley White was also thanked for her service on the board.

George Laszuk, Office Co-ordinator for nearly 19 years, retired at the end of 2022. George tackled many daily office tasks, organised many mail outs with volunteers, he was part of the team to organise and attend all seminars, conferences and also represent Polio NSW at disability expos. He fund raised by selling raffle tickets at all functions and secured donations from his local Lions Club. His loyalty and commitment to Polio NSW has been appreciated by both members and the Board.

It is always appreciated when a member submits a 'story' for our newsletter. Rosalie Cogger-Collins' short story about herself and her sister Gloria's polio journeys is called **Resilience – A Polio Story**. Rosalie and her sister Gloria both suffered after contracting polio in the early 1950's. Her sister suffered with paralysis whereas Rosalie suffered with lung, diaphragm and throat injuries and now they are both dealing with Post-Polio Syndrome. *"I thought this story maybe interesting for people who are suffering with this condition"* wrote Rosalie.

Two webinar reports are included in this issue covering the AGM webinar and a webinar on Feet. The AGM Webinar – **The Polio Experience in Other Countries** had two presenters, both board members, Rosalie Kennedy from South Africa and Vasa Marimuthu from India. They both shared very interesting polio stories and photos including their different treatments for polio. The August Webinar **Feet** by Kyle Perry, Head Podiatrist at **OnePointHealth** Penrith, covered all issues related to the polio foot/leg with solutions to improve problems such as drop foot, fluid retention, swelling and neuropathy.

There is a comprehensive article by Frieda Klotz, **For Some Survivors, Polio Casts a Long Shadow**, covers the early polio epidemics, survivors' early experiences and the treatments that the children endured while being away from their families for long periods of time. A history of the epidemics is included in this article such as the invention of the iron lung and the creation of intensive care units. It also explores the effects of post-polio syndrome and the late effects of polio and how it affected survivors' lives. "Decades after the vaccine, adults with post-polio syndrome are struggling with new symptoms — and looking for answers."

Bruno Bites share information on topics such as Balance, whether President Franklin D. Roosevelt had post-polio syndrome in his later years and everything you need to know about the vagus nerve including what it is, its nerve function, why it is important and what happens if it is damaged.

Network News, Issue 117: June, 2023

This newsletter contains two webinar reports; the first is on **Continence** which was presented by Paula Westwood from the Continence Foundation of Australia which was held in February, 2023. This webinar was very good and offered a clear and concise picture of incontinence and how it can be treated or managed, or in some cases, cured. The second report on **Travel without Limits** was presented by Julie Jones in May, 2023. Julie provided links to articles she had written and she also included extra information that may help with travel planning. Julie has a website packed with additional information to give anyone, with or without a disability, confidence to travel without limits.

On the same theme of travel an article is included by Sonya Meyer's (Consultant for the Confidence Club) on **Travelling with Incontinence: Tips for stress-free holidays**. It has practical suggestions for managing and preparing for a well planned trip.

There is a Q & A article by Dr William DeMayo on **Neuropathy and PPS** which gives an overview to provide a foundation for understanding neuropathy and neuropathic pain and the management of symptoms. He explains what peripheral neuropathy is, treatment and causes.

Dr Marny Eulberg's article on **The COVID Pandemic has been a great Reminder** that Immunisations are for Everyone: Not just for COVID and Not Just for Kids. Many infectious diseases have been eradicated as a result of vaccination such as Smallpox, tetanus, diphtheria, measles,

mumps and/or chickenpox. It lists the schedules of vaccinations for infants as well as for those over 50.

The full article by Hayley Bennett on **The Vagus Nerve: Everything you need to know**, is included in this newsletter.

Millie Malone Lill, Editor of Polio Perspective has written a personal, humorous and entertaining 'tale' called **Laziness...AYE or NAY?** Millie discusses the pros and cons of saying no and asking for help.

Support Groups

Ella Gaffney, Support Group Coordinator

This year's annual report is very short due to the closure of more support groups as a result of general ageing, health, COVID and natural disasters including floods and fires in different areas. There are only a few support groups that are active now.

If you or anyone you know would be interested in starting a Support Group in your area, please get in contact with me or Polio NSW office:

Ella – mobile: 0407 407 564, email: legaff@bigpond.com.

Polio NSW – Phone: 02 9890 0646, email: office@polionsw.org.au:

Following are the Annual Reports from the active support groups:-

ALBURY/WODONGA	Convenor: Margaret Bennie	02 6021 5568
-----------------------	----------------------------------	---------------------

Our group is still active, we meet 4 times a year at the local Commercial Club but our numbers have gone down but we still have about 6 to 8 people at a time. I feel it is an age thing and some just cannot get out anymore. Over lunch we discuss all things relating to our post-polio problems and exchange names of Doctors, Physios, Myotherapists, Podiatrists, and even who was the best driving instructor as we are getting to the stage when we have to be tested for our licenses. I try to keep in contact with the ones who no longer can come.

We also get the Polio NSW *Network News* which has a lot of information and keeps us up-to-date.

AUSTRALIAN CAPITAL TERRITORY	Convenor: Brian Wilson	02 6255 0875
-------------------------------------	-------------------------------	---------------------

The ACT Support Group is still not active. I recently emailed all our members seeking how they were going and only had 3 out of 22 replies! I am planning a group luncheon early December so will see how that goes.

One member, Margaret Smyth, has moved to Adelaide for a warmer climate and to be near family.

CENTRAL COAST	Convenor: Wayne Woolley	02 4342 6145
----------------------	--------------------------------	---------------------

Not much to report from the Central Coast. We are still holding a monthly meeting at the Kincumber Neighbourhood Centre, with generally between 3 and the full membership of 5 joining in for a friendly get-together with cake and coffee. I also occasionally arrange a coffee or lunch mid-month, which is well attended.

The meeting is held on the first Saturday of the month from 10am to noon. We appreciate the very convenient parking right outside. I think the use of a walking stick has become compulsory for all of us.

HILLS DISTRICT	Convenor: Susan Ellis	0466 271 120
-----------------------	------------------------------	---------------------

Our meeting is held on the 2nd Wednesday of every month at West Pennant Hills Sports Club from 10:30am to noon. After our meeting we enjoy lunch in the club's restaurant. Attendance on average

is 6. The format of our meetings is informal but allows each individual to speak in turn allowing for full group participation and discussion.

It is always a productive time spent together while sharing life experiences, swapping helpful advice with laughter and friendship. Shirley provides transport for one or two members to enable them to attend which is much appreciated

A treat for our group was to organise a special Christmas Lunch in December 2022 at an Italian restaurant instead of the club. Partners were also included bringing our numbers up to 12 for lunch.

PORT MACQUARIE **Convenor: Gail Hassall** **portppsg@gmail.com** **0432 881 237**

Unfortunately, numbers have dwindled during 2022/23. Two people have moved, and a couple of members have become more disabled or have other health problems and are unable to attend. We maintain around 30 members on the mailing list but only about 8-10 attend support meetings. Members who are able to attend still wish to do so.

Support Group meetings are informal and include morning tea, an exchange of information and an opportunity to discuss issues pertinent to each person. In addition to a Christmas Lunch at a local club we now have two lunches each year to have a social catch up rather than “talk shop”. There are around 10 happy people who attend these lunches.

NORTHERN RIVERS **Convenor: Rosalie Kennedy** **0412 827 926**

The Northern Rivers Post-Polio Support Group has not had regular meetings over the past financial year 2022-23.

Due to the devastation from floods in our towns and villages, and other disasters in our area, it has been difficult to get together. I have seen a few members online at Polio Australia’s monthly Polio Support Groups, including the NDIS Group run by Devalina Bhattacharjee.

In the coming year, perhaps I can get volunteer help with creating posters and advertising locally for the support group to re-start. The floods and rising fuel (and other) costs have played a big part in getting to venues due to the geographic spread in rural areas like ours.

Online Support Group Report

Rosalie Kennedy

As of last July 2022, Gail Hassall and I continued to share the paid role that Stephanie had done the prior year. Gail organised the Webinars and I did the Support Group activities.

My activities involved running the Support Group, introducing and organising a Monthly Polio Human Library Book for Polio NSW members. Human Library Books are not a new concept as the idea originated in Denmark 23 years ago, and during the Covid19 Pandemic it moved online. Research from the mental health outcomes and socialising benefits of this activity is very positive. As mobility and health issues continue to impact members from travelling to meetings this online format allows members to participate 100% from their own home.

Human Library books and book readers are an interactive event between a ‘book’ and a ‘reader’ to get the chance to hear the life stories of others, and to share their news and achievements of their lives, through living with Polio. The reason for introducing this idea was a way to improve the participation and socialisation and well-being of members. There are privacy protocols around the Human Library Book events, hence Registration is required and this needed to be explained. To introduce the idea and to explain how the Polio Human Library would work, I did power point presentations to the Polio NSW Board and to the online Polio NSW Support Wednesday morning group and invited them to Register to become a “book”. The first Polio Human Library book session ran in July, and then sequentially on the 3rd Wednesday of each month over the next 3-6 months. They were well attended and received. The only reason that they did not continue, was that I ran out of time. Due to the resumption of my casual work outside of polio, and the hours needed to arrange,

advertise, make bookings, and source a Polio Human book and then run the Zoom Meetings, I found it difficult to continue.

During this time, I also attended an International Online Human Library Book session, organised from Norway involving hundreds of people from across the World – on a Weekend in May 2023. It was an enlightening and fascinating event and I noted that the event required an assistant to help with the IT and organise the ‘readers’ into smaller groups (no more than 6 at a time) for each Human Library Book.

I have continued to think about ways of organising and running the Polio Human Library book over the last months before July 1st, 2023, and I hoped for more help to get more Members of Polio NSW to attend the sessions, and to come forward with their stories to be “read” by others. This way of sharing voluntarily and with interest and respectful listening, is a deeper manner of mutual support and allows for members to learn and become fascinated by new and interesting events. It also improves members’ emotional and social health and well-being when they are engaged and connected to people who face similar health and well-being issues. This online forum fills a gap for people with mobility issues, and targets members who find it difficult to get to a face-to-face group.

My hopes for the future upcoming 12 months are:-

1. For the Online Polio Human Library concept to continue to develop with more assistance ie I desperately need IT savvy Volunteers to help with advertising and information sessions into the future, and perhaps become a segway into a series of Polio Human Books/Library Podcasts.
2. For the Board to consider developing training of specialist skilled Volunteers to support people living with Polio with managing the more complex aspects of reaching out to the wider community and their partnerships with Disability agencies (through having links with a certified TAFE or Uni course)
3. Polio NSW Board to consider applying for a grant to contract a person with expertise /equipment to assist Polio Support Groups where members are ageing and unable to get to face-to-face Conferences and Forums.

Webinar Report

Gail Hassall, Online Webinar Co-ordinator

Nutrition was held in July 2022 and was presented by Melinda Overall, Nutritionist and Counsellor. Mel gave a dynamic presentation in which she discussed why food matters and the digestive changes that come with ageing. Especially of interest was polio specific advice regarding protein - the average person needs 1 gram of protein per 1kg of body weight, but polio survivors need 2 grams per 1 kg of body weight for muscle maintenance. Mel provided recipes and tips on managing our diet and easy food swaps for when we are fatigued. It was a very interesting discussion given that we all have questions on how to eat well and maintain a healthy weight range.

Feet, was presented by Kyle Perry, Podiatrist and was held in August, 2022. Kyle talked about polio FEET and how to care for them. This presentation covered how the polio foot differs, fluid retention, neuropathy and the EnableNSW program. This was another interesting presentation and well attended.

The Polio Experience in Other Countries was presented on 30th November, 2022 prior to the AGM. Two members of the Polio NSW Board presented their life experience of having had polio – Vasa Marimuthu from Pondicherry, India and Rosalie Kennedy from Durban, South Africa. Both experienced different medical treatments and in Rosalie’s case she also had to deal with the political upheaval of the Apartheid movement in South Africa.

The first webinar of 2023 was in February on the topic of **Continence** and was presented by Paula Westwood, from the Continence Foundation of Australia. A very good presentation that offered a clear and concise picture of incontinence and how it can be treated or managed, or in some cases, cured.

Travel Without Limits was held in May and was presented by Julie Jones, who created the website “Have Wheelchair will Travel” and the magazine “Travel Without Limits”, Julie said she aims to inspire educators, therapists, carers, and people living with a disability. The webinar provided many useful strategies and tips on travelling and Julie also included links to articles on her website for places and ideas she recommends.

In June, 2023 **Maintaining a Satisfying Life** was presented by Senior Occupational Therapist, Linda Walters, who had presented at the Polio NSW Conference in Port Macquarie in 2018. The webinar included information on how an Occupational Therapist works and how we can use their services for a wide range of situations. She included key occupational therapy interventions and included strategies such as energy conservation – the three Ps, Perspective, Prioritise and Plan. Linda also discussed mobility aids/assistive technology, the reasons we may need them, identifying reasons why we wait too long to the detriment of our mobility, and starting the process of getting the appropriate equipment.

It had been intended to cover the topic of **Oedema Management** but trying to find a person who specialises in the area has not been easy, requests have either been ignored or therapists have been unable to fit a webinar into their busy schedule or have been uncomfortable with the online webinar platform. Hopefully this webinar will occur during the next financial year.

One of the webinars in the 2022-23 program was to be **Navigating My Aged Care** but this may not happen until 2024. The advice from practitioners has been to leave this topic until major changes in the My Aged Care system have been established and assessment staff has become more familiar with the changes.

I would like to thank Merle Thompson, Rosalie Kennedy, and Gillian Thomas for all their assistance and support with the webinar program this year.

External Support

Polio NSW continues to maintain harmonious relations with the Northcott Society which provides us with office space. The Society’s continuing commitment to assist with the production and distribution of Polio NSW publications, particularly *Network News*, by utilising the help of young people on the Vocational Skills Program is likewise greatly appreciated.

Board Attendance Record

Merle Thompson, Secretary

COMMITTEE 2022-2023	NUMBER POSSIBLE	NUMBER ATTENDED	COMMENTS
Gillian Thomas	7	7	
Susan Ellis	7	7	
Merle Thompson	7	7	
Alan Cameron	7	5	
Nola Buck	3	2	Did not re-stand at 2022 AGM
Ella Gaffney	7	6	
Gail Hassall	4	3	Stood aside to take employment 2022
Geraldine James	4	4	Appointed Nov 2022
Rosalie Kennedy	4	4	Stood aside to take employment 2022
Vasa Marimuthu	7	7	
Bill McKee	7	7	
Diana O’Reilly	7	6	
Esther Smart	3	2	Appointed Nov 2022
Shirley White	3	1	Did not re-stand at 2022 AGM