



POLIO NSW

Supporting polio survivors and their families since 1989

Formerly Post-Polio Network (NSW)

Polio NSW is a member of Polio Australia

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2021-2022 ANNUAL REPORT



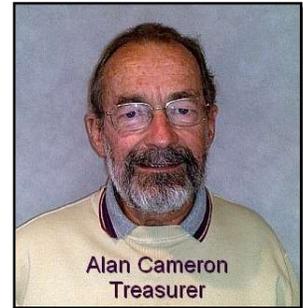
Gillian Thomas
President



Susan Ellis
Vice President



Merle Thompson
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Alan Cameron
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Nola Buck
Network News Co-Editor



Ella Gaffney
Support Group Coordinator



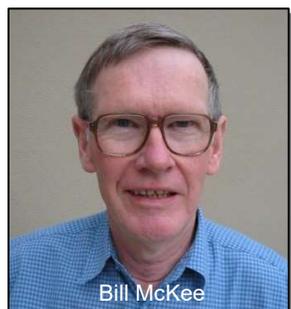
Gail Hassall



Rosalie Kennedy



Vasa Marimuthu



Bill McKee



Diana O'Reilly



Shirley White

Polio NSW 2021/2022 Board

From the President

Gillian Thomas OAM

The Board's focus this year has been on the successful delivery of a NSW Government funded project which has enabled us to extend our support beyond the previously necessarily-limited face-to-face meetings. The project has enabled our engagement on a much more regular basis and across our whole membership base. As shown in the various reports here, online engagement has been embraced by members and now forms the core of all our activities. Building on this year's experience and with momentum growing, we are looking forward to consolidating and sustaining the work in the coming year.

Social Sector Transformation Fund Project

Merle Thompson OAM, Secretary

The NSW Government budget handed down in November 2020 included provision for a new program. In April 2021 applications opened for grants in the program which was titled the Social Sector Transformation Fund. The aim of the program was to provide *“grants for small and medium-sized charities and not-for-profits working in health and social service to help them modernise their operations, so they can remain efficient, effective and viable.”*

The Polio NSW Board assessed that the organisation was eligible and within the stipulated one-month period prepared two submissions – one for each of the \$20,000 and \$50,000 available grants. Polio NSW was successful in obtaining a \$50,000 grant. This is the first time the organisation has received government funding.

The summary of the project included in the submission was:

Polio NSW is a membership-based peer-group organisation providing information and support services to polio survivors, their families and carers. The project will employ an Online Program Facilitator to assist us in developing the skills required to establish resources and methodologies to conduct online webinars and state-wide interactive support programs. Polio NSW members are predominantly older people with disabilities and mobility impairment. Online programs will ensure that it is still possible to provide them with information and support as attendance at face-to-face activities is becoming very difficult. Such programs will also improve access to our services for those in regional areas.

For some years the Board has been concerned that the number of members attending seminars or other activities had decreased and would continue to do so as members age and their level of mobility and independence declined. The COVID-19 pandemic meant that during 2020 and 2021 we were not able to have any face-to-face activities. It was considered that online seminars, webinars and support groups would enable Polio NSW to continue to provide information and support to members. The Board was also aware that many members do not have access to computer-based programs or the confidence to access these.

The application stated *“This project will improve services by: ~ Providing online webinars which will enable participants to still obtain information from polio-informed experts and also provide material for inclusion in newsletters. ~ Extending direct access to information for those who were never physically able to attend in-person education events. ~ Extending direct access to information for those in regional areas who previously have seldom had the opportunity to attend face-to-face education events. ~ Making recorded webinars available for those not able to participate on the day, and for future access by all. ~ Having online peer-support programs available to everyone, not only those in areas where there is a local group and those able to attend meetings.”*

The project has been managed by Gillian Thomas OAM, President, and Merle Thompson OAM, Secretary.

Recruitment of a suitable project officer proved very difficult. In order to be able to proceed, Stephanie Cantrill, part-time Community Liaison Officer for Polio Australia, agreed to work for Polio NSW for ten hours per week. Steph initiated both the online seminar program and online support group and made very good progress. Steph continued in the role until late April 2022 when she resigned from both Polio NSW and Polio Australia. There was no time to recruit anyone to continue for the final two months. Gail Hassall and Rosalie Kennedy stood down from the Board in order to be employed to continue the project and worked ten hours per week each.

Despite the difficulties of a late start and shorter working week much has been achieved.

Services to members previously were confined to two seminars per year, with one to three speakers, small localised support groups and quarterly newsletters. Age and disability issues had reduced the number attending any activities to around 10-15% in total. All face-to-face activities were discontinued in the pandemic. The project has enabled major adaptations: all members with email addresses now receive eNewsletters and/or program updates regularly; the first on-line support group has been active for six months and is now incorporating a Human Library project; within a period of only seven months there have been six online seminars/webinars, two with three or four speakers and the others with one presenter. Members previously unable to participate for disability or geographic reasons can now do so. The sessions are recorded and made available publicly to members. The information is still provided in the newsletters for those without computer access.

By the time the project was to be completed on 30 June, less than 60% of funds had been expended. There seemed to be a strong possibility that an extension into 2022-2023 would be available to continue the initiatives and fully expend the grant.

Polio NSW Office

George Laszuk, Office Coordinator



George Laszuk
Office Co-ordinator



Fatma Alameddine
Admin Assistant



John Doyle
Admin Assistant

The Financial Year did not start well as we were forced to lock down the office once again until 11th November 2021 because of COVID-19. Then, unfortunately, John Doyle had to go on sick leave until the 24th January 2022 due to ill health. He resumed his duties in February 2022 only to resign in June 2022 due to his failing health. John had worked in the office of Polio NSW for over 10 years. A farewell was held in appreciation of his years of dedication to our organisation. He will be greatly missed.

At the moment Fatma and I are trying to stay on top of things. I collect the mail from the post office, do the banking, answer all correspondence, which includes electronic and paper, and of course answer telephone queries. Fatma spends most of her time on MYOB which is our financial computer program. We both maintain the membership database and the filing.

With the help of Nola, Merle, Gillian and Shylie, office records going back more than 20 years were sorted, filing cabinets cleaned up and paperwork disposed of, a task that was well overdue. Now that we use computers to store documents we don't need to physically store this material which was taking up valuable floor space.

Network News

Nola Buck OAM, Co-editor

The year under review, July 2021 to June 2022, has seen the Network embracing technology such as Zoom as it seeks to engage members, many of whom are unable to physically participate in face-to-face meetings and seminars. This has been a positive from COVID-19 lockdowns, the realisation that although physically unable to gather and meet, we could see each other, converse with and enjoy each other's company via a computer screen.

The acceptance of communicating via 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, so as those members who have no access to a computer are not deprived of the information available via the webinars.

Despite the closure of the office during the lockdown, three newsletters were published and distributed. The following is a summary of the content of each newsletter.

Network News, Issue 112

The Board having decided to increase its use of technology to present seminars to members applied for a grant from the State Government and were successful in receiving \$50,000 to employ an Online Engagement Officer to develop resources to provide training to ensure Polio NSW and the polio community have the skills required to conduct and participate in online webinars and interactive support programs.

The stories of three members were included in this issue: Pat Featherstone, a well-known member from Sydney who moved to live with her daughter and how having her mother live with her opened a window to another world for her daughter's family; George Laszuk, a baby of migrant parents who contracted polio soon after arriving at a Migrant Camp; and the story of Margaret Gourley who celebrated her 90th birthday on 16th July 2021.

Helpful and interesting articles were included from Dr Richard L Bruno on the topics of Exercise, Slow Gut and Polio Survivors, and Steroids – the Good and the Bad – and an article from the *Polio Survivor*: an answer by Dr Marny Eulberg to the question: Is Post-Polio Syndrome Progressive?

Generic articles included Accessible Beaches Programme, Become a Pen Pal, and Disability Gateway, an Australian Government service connecting users to information and services.

Network News, Issue 113

This Newsletter contained a variety of articles – the Board members for the year 2021-2022, which included two new members, Rosalie Kennedy and Vasa Marimuthu, and the appointment of Stephanie Cantrill as the Online Engagement Officer. As reported elsewhere, Steph's role was to educate members of Polio NSW in the use of technology to make it easier for them to participate in online events, such as the 2021 Annual General Meeting.

Articles of members' activities included the receipt of the Award of OAM to Nola Buck for services to people with disability and to the community; My Polio Story by Russell King; and an article which appeared in The Guardian on 17th October 2021, prompted by the COVID-19 pandemic and the community's response to it as compared to its response to the polio epidemics.

As not all members are able to participate in online projects, every effort is made to include the contents of those projects in the newsletter, such as the presentation by Steph Cantrill on “Emerging Out of Lockdown”. Steph has also written a step-by-step article on accessing Zoom to make it easier for members to participate in webinars.

Another positive from our increasing use of technology is the online Support Group. Members can now relax in the comfort of their homes, meet other members and share their experiences of living with polio.

Polio specific articles included the Good and Bad Leg which is a study of how a limb appears unaffected by polio, but an EMG reveals that there is damage to that limb. Upside Down Polio is an illustration of how, in order to overcome weakness in lower limbs, the use of upper limbs can cause over-use to upper limbs such as arthritis in shoulders.

Network News, Issue 114

This newsletter contains a report on the progress of the online education project which the Engagement Officer was employed to implement. With Steph Cantrill leaving the organisation, two Board members with appropriate qualifications stood down from the Board and filled this vacancy. Three webinars have been presented, the first on Speech and Swallowing, a transcript of which is included in this newsletter.

Polio Australia also presents webinars and two held in March 2022 were Managing Post-Polio Pain, and Smart Home Technology, transcripts of which are included in this newsletter.

From Bruno Bytes on the topic of Fatigue and keeping an Activity Log, followed by Dr Marny Eulberg’s article, Fatigue – It Makes Me Tired; and, from Millie Malone, Lill, Perspective.

Gillian, Sue and Nola would like to thank the Polio NSW members for their feedback and their contribution of articles, particularly those on their personal stories of coping with polio, and also Northcott Vocational Skills Program members for their assistance in distributing the newsletter.

Support Groups

Ella Gaffney, Support Group Coordinator

We were all hoping that the financial year 2021-2022 would be an improvement on the previous year, I guess it has, if only slightly.

Due to COVID-19, ageing and health reasons, a number of support group have suspended activities. However, there are still a few groups meeting on a regular basis.

The Polio NSW online Support Group commenced this financial year. The first of the online group meetings was organised by Stephanie Cantrill along with the Polio NSW team.

The Online Support Groups are now run by Rosalie Kennedy and feature the “Polio Human Library Book”. This is very interesting as members can share their living book. The group zoom meeting is held on the 3rd Wednesday of the month. If you would like to join the group members can contact Rosalie for more information – rkennedy11@hotmail.com.

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

Ella – Phone: 02 6327 1217, Mobile: 0407 407 564, Email: legaff@bigpond.com.

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

Following are the reports received:

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

We meet in the local Commercial Club where we can order our meal for lunch and sit and talk, we all think that the talking is most important. We have met twice this year and soon to meet again. The first meeting we had 12 people and the next 8. We will keep going for as long as we can. Thanking you, Margaret Bennie, Albury Convenor.

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

There is very little to report from the ACT Support Group this year. Our last regular meeting was in February 2020 and then COVID-19 hit.

We enjoyed our Christmas Party in December 2020 and we managed a luncheon in June 2021 in between lockdowns!

I regularly communicate with phone calls and emails but that's about it. Now as we start to get back to some normality, we'll see what next year brings us.

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

The Central Coast Polio Support Group is still meeting on the 1st Saturday of the month at the Kincumber Neighbourhood Centre (KNC). However, we are down to 5 members, and have had to cancel most meetings as only one other member confirmed attendance.

We will be discussing options on continuing the Group. The rental cost of the meeting room at KNC exceeds our income. Alternatives include meeting at a cafe/restaurant for coffee/lunch on a weekday, as Saturday is not always suitable for some members.

Our meetings when held are good fun, perhaps leaning to social rather than medical issues, unless there is a specific polio subject.

I will notify you if there is a change of day/location.

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 bistro. Attendance varies between 6-8 members. The format of our meetings is informal but allows each individual to speak in turn allowing for full group participation.

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. We are fortunate to have the support of the club which provides us with a private room for our meetings. This assists in hearing everyone's voice without interference from the usual club noises!

A treat for our group was to organise a special Christmas Lunch in December 2021 at an Italian restaurant instead of the club.

PORT MACQUARIE **Convenor: Gail Hassall** **02 6581 4759 / 0432 881 237**

Membership: Total number of members: 30
Average members per meeting: 10-23

This year we welcomed another new member and his wife into our Group but unfortunately, we lost two members. Currently we have 30 people on the mailing list.

This year has run quite smoothly without the interruptions of COVID-19 restrictions. And we have been able to continue meeting at the Port Macquarie Library which is working well.

Meetings are both an opportunity to exchange information and have a social catch-up, and generally we have about 10-12 people attend. This year we have also included two social occasions meeting for lunch at a local club and will do so again with a Christmas lunch in December.

Although we only meet six times per year, we keep in touch between meetings with a short newsletter that includes a report of the previous meeting and any other items of interest especially for those unable to attend meetings.

Online Support Group Report

Rosalie Kennedy

The Polio NSW Online Support Group has been running Zoom Meetings this year, thanks to a very welcome government grant. The group was initially organised and run by Stephanie Cantrill and Team Polio NSW.

The Support Group Zoom Meetings have alternated with Polio NSW run webinars, an online workshop and presentations on Zoom. Gail Hassall and I have been sharing the role that Stephanie held. Gail organises the Webinars and I run the Support Group. This has taken place since late April this year.

Members of Polio NSW are invited via email to join the online meeting, and subsequently given a Zoom Link to the meeting. The process has been running smoothly and polio survivors have been quickly learning how to adjust to this manner of communication.

During the time that I have taken over from Stephanie I have run a Group on the 3rd Wednesday of each month and have been introducing a new way of member sharing their life-stories and other unique experiences that have impacted their lives. 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. This targets members who find it difficult to get to a face-to face support group. The Group is called the Polio Living Library Book and we have had information sessions and last month we had a member share their Human Library Book – of themselves – it was well received. I hope to get more people to come forward with their stories.

There is still a contingent of people who, understandably, find the technology of online meetings too difficult to manage/arrange, so they are informed via newsletters and other methods.

Webinar Report

Gail Hassall, Online Webinar Co-ordinator

Following the resignation of Stephanie Cantrill in April, the role of the Online Engagement Officer was taken on by two of us: Rosalie Kennedy is responsible for online support sessions, while I have managed the education aspect, including planning, arranging and running webinars.

Before we took the plunge into the job, Steph conducted training in the use of Zoom, Try Booking, Canva and Facebook, which I have to say stretched the brain cells a bit.

A couple of webinars were already in the planning stage, one being Retirement Village Living, which was presented by Merle Thompson and a panel of Polio NSW Members including Nola Buck, Sue Ellis, and Chris Kuen.

The second webinar was Fatigue Management conducted by Advance Rehab Centre.

The webinar in June was Falls Prevention with exercise physiologist, Kristen Cox, who did an excellent presentation that rated very highly with all the participants.

Melinda Overall, who is a member of the Polio Australia Clinical Advisory Group, gave a very interesting webinar on Nutrition. This webinar was also rated very highly.

Unfortunately, with the first two presentations there were a few glitches and while webinars have attracted both positive and negative feedback, the positive feedback outweighs the negative. We learn from the comments and each webinar get a little better.

A Webinar Feedback form was sent to all those who registered for all four webinars and the feedback received was very positive. The form also asked for suggestions for future webinars and the responses have offered a number of interesting topics.

I would like to acknowledge Merle's help and support since I took on part of the job. I am very grateful for her assistance, and I also extend my thanks to Gillian and Rosalie for their support.

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 2021-2022

Merle Thompson OAM, Secretary

	Possible	Attended	Comments
Gillian Thomas	7	7	
Susan Ellis	7	7	
Merle Thompson	7	7	
Alan Cameron	7	7	
Nola Buck	7	6	
Ella Gaffney	7	5	Meetings missed were on one day
Gail Hassall	5	5	Stood aside to take employment
Rosalie Kennedy	2	2	Stood aside to take employment
Vasa Marimuthu	4	2	Appointed November 2021
Bill McKee	7	6	
Janette McKenzie	3	3	2021 only
Diane O'Reilly	7	4	
Shirley White	7	4	Email meetings are difficult