



# Cancer Voices NSW

## Annual Report 2019

Presented at the Cancer Voices NSW Annual General Meeting

Friday, 21 February 2020

Woolley/Lawson Rooms

Level 1

Sydney Mechanics' School of Arts Building

280 Pitt Street

Sydney



*Cancer Voices NSW provides the independent voice of people affected by cancer, working to improve the cancer experience of the estimated nearly 48,000 people who are diagnosed in our state each year.*

*Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this, we work in partnership with providers of these services, ensuring the patient perspective is heard.*

### **Vision**

The voice of people affected by cancer

### **Mission**

To lead and advocate for people affected by cancer

To be at the centre of policy, research evaluation and treatment decision-making

### **Our Values**

- Courage - speak up forthrightly
- Inclusion - cancer, statewide
- Transparency - open to all
- Tenacity - always debate our position
- Collaboration - work with others

## Table of Contents

Chairperson’s report and highlights	Page 3
Other highlights	Page 4
Working with stakeholders	Page 5
Farewells	Page 5
Consumer representation and training	Page 6
Updated CIR guides	Page 6
Speaking out	Page 7
Membership	Page 7
The Executive Committee	Page 7
Financial	Page 8
Reflection and thanks	Page 8

## Cancer Voices NSW Annual Report 2019

It is with pleasure that I present the Cancer Voices NSW 2019 Annual Report highlighting the activities of 2019, our nineteenth year. CVN provides the independent voice of people affected by cancer, working to improve the cancer experience of the estimated nearly 48,000 people who are diagnosed in our state each year. We continued to work across a wide and diverse range of issues and areas which included a strong national focus. CVN has also continued to work in conjunction with Cancer Voices Australia (CVA) and the Australian Cancer Consumer Network (ACCN) facilitated by CVA.

I reflect on a year where there has been a move to and recognition of the power of collaboration and a united voice, demonstrated by the formation of new networks and alliances and forums which provided key opportunities for us to engage and contribute to the national agenda and inform policy recommendations at the national level.

NSW began 2019 with two elections on the agenda. NSW went to the polls in March. This was followed by the Federal election in May. Both elections saw the sitting coalition governments returned, and the health ministers from the previous parliaments each retaining their respective portfolios.

The beginning of new parliamentary sessions at both a state and federal level also provided the opportunity to develop productive relationships and influence change and direction for the duration of these terms.

The media continued to provide a lot of momentum across the health sector identifying the many challenges that face us with cancer having considerable prominence. With so many issues being identified and continuing to be highlighted it was made very clear that serious measures, including collaboration and large scale investment, were required to bring about change to create a health system relevant to the twenty first century and which meets the needs of the Australian community. Opportunities for us to collaborate, contribute and engage on a broad scale to achieve better outcomes for those affected by cancer in NSW and beyond, with both government and cancer and other health organisations, included:

- **Informed financial consent.** Building on the momentum developed throughout 2018, work continued within the cancer community leading to the development of a draft standard for informed financial consent by Cancer Council Australia, BCNA, PCFA and Canteen. This continued to have prominence during 2019.
- **Out of Pocket Costs Transparency Working Group** which was tasked with the development of a national website to provide information to the public about fees charged by specialists in order to make an informed decision. The first version was launched at the end of 2019. We were one of three consumer groups invited to join this working group.
- **Canberra Health Summit** was a two-day gathering in July, of 23 Australian health consumer organisations, representing over 20 million people with the shared ambition to 'improve the health and wellbeing of all Australians through a health system that puts the consumer at its heart; one that draws on the experience of Australians living with health conditions, and embeds consumers at every step of the policy making process'. This is now known as the Australian Patient Advocacy Alliance.
- **National Preventive Health Strategy**, which aims to provide a long-term vision for improving the health of all Australians and stimulate a shift to achieve a better balance between treatment and prevention.
- The inaugural **Cancer Council Australia Cancer Consumer Forum** was held in October to explore policy issues of relevance to all cancer organisations.
- **Consumers Health Forum Members Policy Forum** in November focused on national policies and strategies (short, medium and long term) to provide recommendations to the federal government.

## Other Highlights include

- **The inaugural Sally Crossing AM Award for an Outstanding Achievement in Cancer Research** was announced at the 2019 annual Cancer Council NSW Research Awards Night in March. This award recognises an outcome achieved by a cancer researcher previously funded by Cancer Council NSW, with strong consumer involvement, which has improved the lives of those affected by cancer. The recipient was Professor Murray Norris AM from the Children’s Cancer Institute. This \$50,000 award was made possible through the generosity of the Crossing Family and the Belalberi Foundation in conjunction with Cancer Council NSW and CVN.
- In May several members attended and participated in the inaugural **Australian Patient Network Symposium**, convened to support the health charity sector and strengthen its impact through collaboration. This is now known as the Australian Patient Organisation Network (APON).
- **New Patron** We were delighted to receive confirmation in June that the Honourable Margaret Beazley AO QC, Governor of NSW, has agreed to become **our Patron**. We have been privileged to have had the two previous Governors as the patron of CVN and affiliated Breast Cancer Action Group (BCAG).
- The online release of the **Health Conditions and Insurance Report, “What’s the Risk?”** by Legal Aid NSW in July. This project had its beginnings in Cancer Voices, when in 2015 we identified travel insurance as a key priority. It was then expanded by Legal Aid to insurance issues for those with a wide range of serious health conditions, thus gaining a broader understanding of the experiences of those with health conditions when trying to access insurance products. The report identifies the opportunity for further ongoing collaborative work through twelve recommendations. It was officially launched in August.

The “voice” was heard on many issues during 2019 including:

- *Improved subsidies for IPTAAS to reflect true costs and inclusion of access to clinical trials*
- *Regional and Rural including Hunter New England LHD: rural oncology - meeting future needs*
- *Telehealth*
- *Greater access to radiation therapy services in regional, rural and remote locations*
- *Greater access to end of life & improved palliative care services*
- *Access to lymphoedema services & garments & their associated costs including via the Lymphoedema Action Alliance (LAA)*
- *Adequacy of cancer workforce, especially cancer care coordinators*
- *Support for consumers attending cancer conferences*
- *Consumer engagement in research including our matching service, presentations and training*
- *Improvement of research ethics and governance in Australia via a petition for a national inquiry*
- *Consumers Included program*
- *Affordable access to highest quality care*
- *Reform relating to the TGA, PBAC and MSAC to streamline and increase flexibility for technologies, tests, co-dependent technologies and medicines*
- *Insurance issues for people with major health conditions including recommendations of the health & insurance report launched in 2019*
- *Medicinal Cannabis*
- *Survivorship: including COSA Survivorship Conference in March: organising committee, session facilitators and participants*
- *COSA / Flinders Survivorship conference steering committee*
- *Health literacy*

- *Wider awareness & understanding of the vital role of the carer by providing easy & timely access to support & comprehensive information for them*
- *Access to clinical trials including via the COSA Teletrials Consortium (CVN as a member of the consortium contributed \$5K to this project in 2017) and the Australian Clinical Trials Alliance*
- *Informed financial consent including Cancer Council Australia voluntary Standard for Informed Consent*
- *Cancer Council Australia Rare and Less Common Cancers resource project including involvement of consumers as reviewers & review of draft resources*
- *Consumers Health Forum Australia via Members Policy Forum in October*
- *Medicare Benefits Schedule (MBS) Review Taskforce: updating and alignment of MBS items to reflect latest treatments and technologies, including Colorectal Surgical Response*
- *CCNSW relationship meetings / Advocacy Working Group*
- *NSW Government cutbacks including to NSW Health*
- *NSW Cancer Plan including lack of involvement in the review of the current plan*
- *Victorian Cancer Plan consultation*
- *Draft National Safety and Quality Health Service Standards User Guide for Medication Management in Cancer Care*
- *Review of an early breast cancer survivorship resource*
- *Cancer Australia Expert Working Group update of early breast cancer guidelines*
- *Australian Commission on Safety and Quality in Health Care (ACSQH): Australian Charter of Healthcare Rights - consumer guide, via an online survey consultation*
- *Fertility preservation*
- *Treatment side effects including the importance of patients being informed of the risks associated with all cancer treatment and therapies, short and long-term, to enable patients to be active participants in their treatment path*
- *2020 Sydney Cancer Conference organising committee*
- *National Lung Cancer Screening Consultation - feasibility for a national lung cancer screening program for people at high risk of lung cancer including stigma*
- *Voluntary Assisted Dying legislation in NSW.*

**Note:** More details can be found in our 2019 newsletters Nos 74-76 at <https://www.cancervoices.org.au/news-updates/>

**Working with Stakeholders:** CVN nominees and the group itself continue to work with the wide range of cancer and relevant health stakeholders, strengthening existing relationships and establishing new ones at both state and national levels. Engagement included key state political parties, MPs and their representatives, government agencies, committees, authorities and organisations, cancer agencies and organisations, consumer organisations, educational facilities, research facilities and organisations, medical colleges and organisations.

**Farewells:** As a result of changes during 2019 in the Policy and Advocacy (P&A) Unit at Cancer Council NSW, we thanked and farewelled three long standing members - Carolyn Grenville, Advocacy Network Development Officer, Katie Sheehan, Project Coordinator and Bernadette Roberts, Senior Policy Analyst. Cancer Voices has enjoyed a strong and close working relationship with them over many years.

In July we joined the farewells for the esteemed Dr Helen Zorbas AO, after 9 years as CEO of Cancer Australia. Helen has been a highly regarded clinician and leader in cancer control in Australia over many years, a long term friend to CV from the early days of the National Breast Cancer Centre and supporter of consumer inclusion and

involvement at all levels. We welcomed Professor Dorothy Keefe from South Australia into the role of CEO Cancer Australia.

### **Consumer Representation and Training**

Our representation is across a wide and diverse range of areas. That representation is strengthened by appropriate training which equips us to be more effective in the roles that we take on.

**Consumer Advocacy Training (CAT)** courses are held in conjunction with Cancer Council NSW (CCNSW). In 2019 only one course occurred in March. This two day training equips attendees with a solid understanding of advocacy, the political context in which it takes place and the capacity to plan advocacy campaigns around identified issues. Participants are invited to join Cancer Voices, and this continues to be an important source of new members. This training is currently being reviewed and CVN was invited to join that working group with a new approach to be developed for 2020.

**Consumer Involvement in Research (CIR)** training was held in September with CCNSW, the third year using a format comprising four online modules and a half day face to face workshop. This provided 15 new “graduates” to support our CIR matching program for researchers seeking to work with informed consumers, now a requirement for most grant approvals. Some funders are now requiring a minimum of two consumers for projects. CIR members take on roles in cancer research projects, as Research Panel Consumer Advisors and on Consumer Review Panels. The 2019 research funding cycle saw 102 consumers matched with 68 requests compared to 51 requests involving 67 consumers during the 2018 funding cycle. Requests also come from further afield including interstate universities and research institutions. Requests have been diverse and covered a wide range of cancer types and issues including diagnosis, treatment and rehabilitation, quality of life, chemotherapy and tailoring new therapies.

In 2019 projects included reducing toxicity from cancer treatments; cancer risk factors; managing and enhancing family carer involvement through an online program; new drug research and the use of novel treatments; best practice guidelines; risk factors for different cancers; genetic testing; repurposing of immunotherapy drugs

Cancer Voices members continue to speak at conferences, workshops and symposiums about the benefit of the CIR Program and the value that consumers bring to cancer research. We now have approximately 130 consumers actively involved in CIR. Lee Hunt has been administering this important program since 2015.

**Updated CIR Guides:** Guides originally produced in 2014 to assist both consumers and researchers working together on research projects to understand the respective roles and how to maximise the experience have been updated and are available on our website. Additional tips and hints have been included in both guides along with a link to the recently launched Australian Cancer Trials Consumer Involvement and Engagement Toolkit

**Consumers included (Ci):** Our Consumers Included logo ‘seal of approval’ program for consumer inclusion continued, with the Ci logo approved for use for five cancer related conferences during 2019.

**The Written Word:** We have updated and reprinted our CVN brochure and it is also on our website. We began the year with the 74<sup>th</sup> edition of our newsletter. Three 12-16 page newsletters were published during 2019 and emailed to members and stakeholders. They are also available on our website for wider access at <https://www.cancervoices.org.au/news-updates/> They provide more details on all our activities throughout the year. Many thanks to all who contributed to our newsletter by reporting on issues and their activities in the interest of those affected by cancer. Our thanks also to the Cancer Council NSW and the Cancer Institute NSW for their regular contributions to our newsletter. Cancer Voices is also responsible for the Cancer Voices Australia

(CVA) *News Updates* which were incorporated into the CVN newsletters. Major submissions, reports, new and revised position statements, reviews and posters can also be found on the CVN website, whilst those related to national issues are accessible on the CVA website at <https://www.cancervoicesaustralia.org/>

**Speaking Out:** During 2019 members continued to attend meetings, workshops, seminars, events and conferences. This is a very effective way to contribute the consumer view along with taking the opportunity to network and keep up to date not only with cancer matters but also across the wider health continuum. CVN representatives continued to give invited addresses and presentations, to liaise with government including key political parties, MPs and their staff and to contribute to media discussion.

**Membership:** We continue to welcome new members who are welcome to join our advocacy and CIR activities.

Sadly, due to the nature of cancer, we also lose members.

Membership is steady with group members at 65, and individual membership at 365. Newsletters are also sent to 150 organisations and health professionals who want to be informed about CVN and issues for people affected by cancer.

We remain a completely independent and voluntary advocacy organisation with our success entirely dependent on the collective efforts of members, consumer representatives and in particular, members of the Executive Committee. Special thanks to the wonderful behind-the-scenes support by Kathryn Leaney, who continues to format our newsletters, facilitate our CVN EC strategic workshops and assist with document updates.

**Cancer Voices SA (CVSA):** CVN and CVSA continue to collaborate. The two organisations continue to work closely together particularly on policy, reviews, guidelines and submissions.

### **The Executive Committee**

**Vale** Elaine George and Peter Brown. Sadly, we acknowledge the passing of two Cancer Voices EC members.

**Elaine George**, who was an EC member during 2017, passed away in October 2018. In the short time we knew Elaine she certainly lived by her “finding purpose in the inescapable” making every moment count and was very passionate about raising the profile of metastatic breast cancer.

Long standing EC member **Peter Brown** (a member since 2005) passed away in February. Peter was also very active with both St George Hospital and South East Sydney Local Health District (SESLHD). A passionate and tireless advocate who would have turned 90 in December. Further details on Peter’s involvement as a consumer advocate at <https://www.cancervoices.org.au/wp-content/uploads/2019/07/Peter-Brown-CVN-Remembers-April-2019.pdf>

**The Executive Committee (EC):** Following our AGM the CVN EC meetings were held every two months either at Health Consumers NSW (HCNSW) in the CBD or by teleconference. We have continued to make great use of teleconferencing and have met out of session as necessary. Members for 2019 were Elisabeth Kochman (Chair), Murray McLachlan (Deputy Chair, Hon Sec), Shirley Baxter (Deputy Chair), Sandra O’Sullivan (Treasurer), Lee Hunt, Bev Noble, Roberta Higginson, Jan Munford, Sarah Lukeman, Lillian Leigh, Kathryn Leaney and Dan Kent. Members of the EC sit across a wide range of special interest areas. Teamwork has underpinned our ability to cover key issues and achieve desired outcomes. Former EC member David Campbell has continued in the role as an Advisor on political matters. We thank him for his ongoing support. Special thanks also to CVN EC member Dan Kent, who facilitates the ACCN on behalf of CVA.

**CVN EC Workshops:** Following our AGM in February, Executive Committee members participated in a strategic planning workshop. A follow up workshop was held in May. A lot of time and effort has gone into the development of Action Plans covering key operating areas. Teleconferences have been used to progress the development of the outcomes of our workshops based on the analysis of our 2018 Members survey.

Teamwork is a crucial element and we have continued to see that at work this year through our planning work and willingness to engage and support each other. I would particularly like to acknowledge the ongoing support of both Murray McLachlan and Shirley Baxter during 2019.

**Financial:** The Treasurer's Report for 2019 is presented separately. As a 100% voluntary organisation we are grateful for all donations received, no matter the amount, as it all helps.

Special thanks to Sandra O'Sullivan who has continued to support Cancer Voices as our Treasurer since 2001.

### **Reflection and Thanks**

We cannot do what we do in the interests of people affected by cancer without a lot of encouragement and support. We recognise the valuable volunteer work of members and appreciate and acknowledge pro bono services including Health Consumers NSW who, for the third year, provided us with a convenient location for our meetings during 2019, and Geoff Vass from Cadzow TECH Pty Ltd who has supported us with IT and website needs and issues since 2016. A BIG thankyou to all.

To members of the Executive Committee and to our nominees who contribute significant time, expertise and effort to work in positions as consumer representatives, in advocacy and advisory capacities with decision-makers, thank you for your wonderful support, enthusiasm, commitment and contribution throughout the year. And of course, thank you to our stakeholders and supporters who respect and seek our views and work with our representatives. Together we can and will continue to make a real difference.

We finished the year with the news dominated by the devastating fires that had and were continuing to affect areas and communities. That had us thinking of the health implications, short, medium and long term, for those directly involved and affected and also for the wider community. That is what advocacy is all about, identifying issues, what needs to be done, by whom and when.

2020 will see Cancer Voices reach a significant milestone – twenty years / two decades providing the voice of those affected by cancer, a rather significant achievement for a 100% volunteer organisation. We are looking forward to celebrating this achievement throughout the coming year.

There is still "so much to be done!" "nothing about us without us"

Elisabeth Kochman, Chair 2019

[www.cancervoices.org.au](http://www.cancervoices.org.au)



**Cancer Voices is the independent, volunteer voice of people affected by cancer - since 2000**