



## **Cancer Voices NSW Annual Report 2018**

Presented at the Cancer Voices NSW Annual General Meeting

Friday, 15 February 2019

Carmichael and Dowling Rooms

Level 1, SMSA 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 over 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*



## Cancer Voices NSW Annual Report 2018

It is with pleasure that I present the Cancer Voices NSW 2018 Annual Report highlighting the activities of 2018, a year of positioning our organisation so that we continued to be strongly engaged at both state and national levels during the year. Our work and representation continued across a wide and diverse range of issues and areas. Increasingly we have seen Cancer Voices NSW (CVN) focused on national issues. CVN has also continued to work in conjunction with Cancer Voices Australia (CVA) and the Australian Cancer Consumer Network (ACCN) facilitated by CVA.

Along with our representative work, we have continued to work on our action plan that resulted from our 2018 Think Tank workshop. Following our AGM in February, members of the Executive Committee participated in a **workshop** which was facilitated by CVN member Kathryn Leaney. One outcome of that very successful workshop was a **survey** of members to enable members to contribute to our future direction. Results of our survey have been published and will form the basis of our 2019 Executive Committee workshop.

With elections at both state and national levels in 2019 CVN was keen to engage with both levels of government. At a **state** level, CVN pursued its **election strategy** and relationship building which included several meetings with MPs and representatives of the major parties. The key issue raised was the need for fair and equitable access with subsidies under the Isolated Patient Transport Accommodation and Assistance Scheme (IPTAAS), including access to clinical trials. Lymphoedema, Palliative Care, Cancer Care coordinators and Telehealth were also raised as also part of this agenda. At a **national** level both CVN and CVA have contributed to the national agenda and policy platform including with Consumers Health Forum Australia and participation in the Federal Ministerial Roundtable. This program of engagement will continue during 2019, whatever the outcomes of the two elections may be.

### **Cancer Voices NSW** is delighted to announce a new research award, ***The Sally Crossing AM Award for an Outstanding Outcome in Cancer Research.***

This award has been a collaboration between Cancer Council NSW (CCNSW), Cancer Voices NSW, the Belalberi Foundation and the Crossing Family. It will “*recognise outstanding achievements in cancer research, inclusion of consumers and delivery of significant benefit to the cancer community*”. This is a generous \$50,000 individual award dedicated to the memory of the late Sally Crossing AM and provided by the Belalberi Foundation and the Crossing Family. The successful recipient will be announced at the annual CCNSW Research Awards in March.

**Achieving our goals:** Cancer Voices continued to work at its core function of providing an effective voice for people affected by cancer. Cancer Voices continued to pursue standing advocacy issues and address new ones as they arose.

The “voice” was heard on many issues during 2018 including:

- *Improved subsidies for IPTAAS to reflect true costs and inclusion of access to clinical trials*
- *Regional and Rural incl Hunter New England LHD; rural oncology - meeting future needs*
- *Telehealth*
- *Greater access to & improved palliative care services – especially end of life*
- *Voluntary Assisted Dying legislation*
- *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*

- *Cancer Council NSW Research Highlights Report 2017/2018 – Consumer Survivorship stories; including participation by CVN members*
- *Cancer Council NSW 5 year strategic plan*
- *Consumers Included program*
- *Affordable access to highest quality care*
- *Access to new drugs via the National Oncology Alliance (NOA)*
- *Insurance issues for people affected by cancer*
- *Medicinal Cannabis*
- *Safety & Quality in Cancer Care. Best practice standards following “chemo dosing incidences” in NSW & SA*
- *Australian Commission on Safety and Quality in Health Care (ACSQH): improvement of the safety and quality of chemotherapy services*
- *Survivorship: including participation in focus groups, appointment to conference committee*
- *Patient Reported Outcomes (PROs) via the COSA 2018 Think Tank "Implementing monitoring of patient-reported outcomes into cancer care in Australia". (Report to be officially launched in March 2019)*
- *Access to clinical trials including via the COSA Teletrials Consortium (CV as a member of the consortium contributed \$5K to this project in 2017)*
- *Cancer treatment options – prostate cancer*
- *Informed financial consent including Cancer Council Australia voluntary Standard for Informed Consent*
- *Clinical practice guidelines for diagnosis and management of melanoma*
- *Low survival and less common cancer resources project including focus group facilitation*
- *Medical Research Future Fund (MRFF) Priorities*
- *Availability and accessibility of diagnostic equipment around Australia*
- *Federal Department of Health Roundtable: (October 2018) including funding for Radiation Oncology (RT) equipment and for additional RT centres in regional / rural Australia*
- *Consumers Health Forum Australia: national health policy platform*
- *Medicare Benefits Schedule (MBS) Review Taskforce: updating and alignment of MBS items to reflect latest treatments and technologies*
- *Therapeutic Goods Administration (TGA): new access strategies for medications*

**Note:** More details can be found in our 2018 newsletters Nos 70-73 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. Engagements includes 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.

**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 were held in conjunction with Cancer Council NSW (CCNSW) in May and October. 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.

**Consumer Involvement in Research (CIR)** training was held in September with CCNSW, the second year using a new format comprising four on line modules and a half day face to face workshop. This provided 20 new “graduates” to support our CIR matching program for researchers seeking to work with informed consumers, now a requirement for most grant approvals. The demand for consumers is strong with 51 requests for consumers during the 2018 funding cycle involving 67 consumers. Requests have been coming from further afield including interstate universities and institutions. Projects cover a wide range of cancer types and issues including diagnosis, treatment and rehabilitation, chemotherapy and tailoring new therapies. Several of our consumers have also been asked to become members of research advisory groups and cancer strategy and development working groups. Consumers have also spoken at conferences, workshops and symposiums. We now have approximately 115 consumers actively involved in CIR. Lee Hunt continues to administer this important program.

**Consumer Review Panel Training** was also held in September by CCNSW where participants gain skills in reviewing research grant applications for CCNSW from a community perspective.

**The Written Word:** We began the year with the 70<sup>th</sup> edition of our newsletter. Quarterly 12-16 page newsletters were published during 2018 and were mailed 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*. During 2018 four 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 2018 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 in the cancer arena. CVN representatives continued to give invited addresses and presentations, to meet with government including key political parties, MPs and their staff and to contribute to media discussion.

**Organisational:** 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.

Group members total 70, and individual membership is 365. Newsletters are also sent to 136 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 team: Sharon Pannewitz who manages our Members Registry and provides labels for our newsletter mailouts and Kathryn Leaney, who continues to format our newsletters and in 2018 also facilitated our CVN EC strategic workshop and provided valuable assistance in shaping our Members Survey and preparing the electronic version. Geoff Vass assisted with the technical aspects of its distribution, along with the all-important IT support we rely on to carry out our activities.

**Cancer Voices SA (CVSA):** CVN and CVSA continue to collaborate. The two organisations have worked closely together particularly on policy, reviews, guidelines and submissions. during 2018.

**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 made great use of teleconferencing and have met out of session as necessary. Members for 2018 were Elisabeth Kochman (Chair), Murray McLachlan (Deputy Chair, Hon Sec), Shirley Baxter (Deputy Chair), Sandra O’Sullivan (Treasurer), Lee Hunt (CIR), Bev Noble, Peter Brown, Roberta Higginson, Jan Munford, Susan Pitt and Sarah Lukeman. 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 taken on the role as an Advisor on political matters. We thank him for his ongoing support. Special thanks also to CVN member Dan Kent, who facilitates the ACCN on behalf of CVA.

Teamwork is a crucial element and we have seen that at work this year. With good planning and a collaborative approach, some members were able to step away from Cancer Voices responsibilities at various times and everything continued to run smoothly. I would particularly like to acknowledge the support of both Murray McLachlan and Shirley Baxter during 2018, particularly during my absence when they ably took the reins.

**Financial:** The Treasurer’s Report for 2018 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 such as newsletter printing and mailing by Cancer Council NSW, Health Consumers NSW for providing us with a convenient location for our meetings during 2018, Geoff Vass and Melissa Cadrow of Cadrow TECH Pty Ltd who ably assist with IT and website needs and issues and Geoff Michels of The Michels Group for marketing and communication advice. A BIG thankyou to all.

To members of the Executive Committee and to our nominees who contribute a lot of 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.

There is still “so much to be done!”

Elisabeth Kochman, Chair 2018

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



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