

Message to Members

With two elections this year now behind us we are at the beginning of new parliamentary sessions at both a state and federal level and have the opportunity to develop productive relationships and influence change and direction for the duration of these terms. We have sent congratulatory letters to Minister Hunt on retaining his portfolio, to Chris Bowen on his appointment as Shadow Minister for Health and Dr Richard Di Natale, health spokesperson for the Australian Greens. Health, and in particular cancer, has had considerable prominence both pre and post the election. So many issues have been identified and continue to be highlighted both during and since the election. It is clear that serious measures are 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.

It is quite some time since there has been as strong a focus at both state and federal level on health issues, and on cancer specifically. This provides us with opportunities to significantly influence decisions that will help improve the lives of those affected by cancer.

One area that has received much attention and scrutiny is that of **out of pocket costs (OOPCs) and informed consent**. A significant amount of work was carried out and a lot of momentum was built through 2018 within the cancer community leading to the development of a draft standard for informed consent. This has been the basis of conference presentations, most recently by Sanchia Aranda, CEO Cancer Council Australia, at the COSA Survivorship Conference in late March. Separately, as a result of the findings of the Ministerial Advisory Committee on Out-of-Pocket Costs there was a recommendation to setup an OOP Transparency Working Group. Prior to

the federal election, we were invited to nominate for this working group. Post the election, and with the return of the Coalition Government, we received confirmation that our nominee, Shirley Baxter, had been appointed to this group. This issue has gained significant momentum with so many stories of bill shock and financial hardship due to OOPCs. Both Minister Hunt and the Chief Medical Officer, Brendon Murphy have spoken extensively about this Government initiative to address the issue. Cancer Voices commends the Government's move to deal with this growing issue. The first meeting was held on 19 July in Melbourne.

July has seen the online release of the much anticipated **Health Conditions and Insurance Report** by Legal Aid NSW. 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.

Vice Regal Patronage: 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 our patron.

Best wishes to all our members, consumer representatives and readers. We hope that you enjoy this edition.

**Elisabeth Kochman (Chair) and
the Cancer Voices Executive Team**



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.



CVN Notice Board



Cancer Council NSW Consumers in Research Training (CiR) 20 September 2019

Cancer Council NSW highly values the community's perspective on cancer research – community members are an essential part of research projects and the research funding process.

Every year, Cancer Council NSW runs free sessions to train consumers to work directly with cancer researchers, and to enable them to help decide which cancer research projects are funded.

If you are a community member who would like to get involved in cancer research, please contact research@nswcc.org.au to let Cancer Council NSW know that you're interested in the next training session in September 2019. The training is free, but spaces are limited.

Further information <https://www.cancer.org.au/about-us/consumertraining.html>

CONSUMER ADVOCACY TRAINING

Next date for 2019 to be advised

Further information can be found at: www.canact.com.au/advocacy_training

or contact advocacy@nswcc.org.au

Note: CVN members are given priority when applying to attend.

SAVE THE DATE – Thursday 26 September 2019

2019 Cancer Institute NSW - Innovations in Cancer Treatment and Care Conference
Sofitel Sydney Wentworth, Phillip Street Sydney

The 8th annual *Innovations in Cancer Treatment and Care Conference* with the theme *equity of outcome in cancer control*, will bring together clinicians, health workers, researchers and people affected by cancer to foster innovation and continuous improvement across the NSW cancer health system.

For further details and to register: <https://web.cvent.com/event/fd146085-7983-47e4-822a-61bdc3808f74/summary?previewToken=68d3e87db8b55dea3087b2dbb4ef7bdb>

2019 Public Seminar Program at the Garvan

The Garvan Institute runs a public seminar series that is free to attend:

Thursday, August 22 2019, 10am–11:30am: ***Stories from the lab***

Thursday, October 24 2019, 10am–11:30am: ***Positive ageing: taking charge of your health & wellbeing***

Tuesday, December 10 2019, 10am–11:30am ***Beyond 2020: healthcare of the future***

Registration is essential. [Register now](#)

Seminars are livestreamed on [Facebook](#). Past seminars can be accessed via <https://www.garvan.org.au/tours-events/public-seminars/previous-seminars>



CVN Committee News

Cancer Voices Annual General Meeting was held 15 February in the Carmichael and Dowling Rooms, Level 1 SMSA Building, 280 Pitt Street Sydney. Peter Crossing AM also joined us. The CVN 2018 Annual Report was presented and is available on our website <https://www.cancervoices.org.au/wp-content/uploads/2019/07/Annual-Report-Cancer-Voices-NSW-2018.pdf>

2019 CVN Executive Committee (EC):

Chair: Elisabeth Kochman
Deputy Chairs: Shirley Baxter
Murray McLachlan
Hon Sec Minutes: Murray McLachlan
Hon Treasurer: Sandra O'Sullivan
Committee Members: Bev Noble, Lee Hunt, Roberta Higginson, Jan Mumford, Sarah Lukeman, Kathryn Leaney, Lillian Leigh and Dan Kent
Advisor: David Campbell

Susan Pitt did not renominate as she has relocated to Melbourne. We are grateful to Susan for her contributions over the past few years and will stay in touch. We welcome the return of Lillian Leigh to the EC. Cancer Voices members Kathryn Leaney and Dan Kent have also joined the EC. All bring a wealth and diversity of skills and experience. David Campbell will continue in the role as Advisor.

Following our AGM in February, Executive Committee members participated in a strategic planning workshop. A follow up workshop was held in May. Our thanks to Kathryn Leaney who facilitated both

workshops. 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.

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. In 2017 Elaine initiated the *Flashmob Dance* event in Martin Place. It was held again in 2018 in Pitt St Mall.

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. For more on Peter including a tribute from SESLHD go to <https://www.cancervoices.org.au/wp-content/uploads/2019/07/Peter-Brown-CVN-Remembers-April-2019.pdf>

Thank you to Health Consumers NSW (HCNSW): We will continue to meet at the offices of HCNSW for a third year. This arrangement continues to foster a closer relationship between our two organisations.



Advocacy Updates

Lymphoedema Action for NSW - - including the Lymphoedema Action Alliance (LAA)

Cancer Voices would like to acknowledge the efforts of Cancer Council NSW staff and volunteers for their campaigning efforts in the lead up to the 2019 State election. They received great support from the LAA. (CVN is a member of the LAA). There was no commitment before the election from either the Government or Opposition which was very disappointing. On a positive note there is now a much greater awareness and understanding of lymphoedema and the need for more public services to manage and treat it. We will all continue to urge the

NSW government to provide funding for these much needed public lymphoedema services and to utilise the therapists that have been trained with government funding. CVN also raised this issue in our meetings with MPs and advisors from the major parties during our 2019 NSW Election Strategy.

Lymphoedema guidelines

The Agency for Clinical Innovation (ACI) "has developed Lymphoedema: A guide for clinical services to identify best-practice management of lymphoedema to support optimal care for people affected by lymphoedema across NSW" available at https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0008/477998/lymphoedema-guide.pdf

Elisabeth Kochman

Insurance issues- just released! Health Conditions and Insurance Report

Cancer Voices is delighted with the online release of this report. Our thanks to CV member Lillian Leigh who in 2015 took our travel insurance issue to her then employer Legal Aid NSW. Legal Aid NSW and Lillian then expanded it to insurance issues affecting those with a range of health conditions. Results from the analysis of the survey of 281 people confirm that those with health conditions frequently experience difficulty and frustrations in securing insurance at a reasonable premium and on occasions face outright denial. The report identifies the opportunity for further ongoing collaborative work through twelve recommendations.

Our thanks and gratitude to Legal Aid NSW for funding this project and compiling this report. To access <https://www.legalaid.nsw.gov.au/publications/reviews-and-submissions>

Elisabeth Kochman

Palliative care announcements

In the lead-up to the 2019 NSW State election, 23 March, both the Government and the Opposition made announcements regarding the provision of palliative care services. The Government allocated \$45million to palliative care, which is to

- add 100 more nurses to the palliative care workforce, with 64 expected for regional and rural NSW;
- increase the number of full-time equivalent palliative care Aboriginal health workers from nine to 18, so that every local health district and network has a full-time position;
- increase use of digital health solutions to improve end-of-life care to people living in rural and remote areas;
- connect young people in regional areas through digital health solutions to the new Adolescent and Young Adult Hospice in Manly, and funding of a senior clinical role to support its staff, and
- support the refurbishment of existing palliative care facilities across NSW, providing a home away from home for patients.

The funding is in addition to the \$100million palliative care package that formed part of the 2017-18 NSW budget.

At the end of February, the NSW Ministry of Health released the *NSW Health End-of-Life and Palliative Care Framework 2019-2024* <https://www.health.nsw.gov.au/palliativecare/Pages/eol-pc-framework.aspx>.

Resulting from the ministerial roundtables held in 2017, and a survey of 2000 people, the Framework will be used by the whole NSW health system with the aim of working together to provide accessible, high quality end-of-life and palliative care. The Framework has five priority areas:

- Care is person centred
- There is recognition and support for families and carers
- There is access to care providers across all settings who are skilled and competent in caring for people requiring end of life and palliative care
- Care is well-coordinated and integrated
- Access to quality care is equitable

The NSW Health End of Life and Palliative Care Committee has been established to provide oversight of end of life and palliative care across NSW Health. Next steps will include the development and publication of an implementation plan.

The NSW Health End of Life and Palliative Care Committee has been established to provide oversight of end of life and palliative care across NSW Health. Next steps will include the development and publication of an implementation plan. Having contributed to the development of the framework through the roundtables and survey, and raised palliative care issues in our meetings with both MPs and staffers from the Government and Opposition through our NSW Election Strategy, one of our challenges over the term of the re-elected NSW Government will be to ensure that it meets its palliative care commitments, and continues to work to making the provision of palliative and end-of-life care as straightforward as possible for people affected by cancer.

Murray McLachlan

Medicinal cannabis matters

Clinical guidance information

Cancer Voices NSW has responded to the opportunity to provide feedback on clinical guidance information. The information has been developed by the Australian

Centre for Cannabinoid Clinical and Research Excellence (ACRE) to support NSW medical practitioners in prescribing cannabis medicines to patients for conditions where cannabinoids (the active chemicals in medical marijuana) are perceived to have some benefit. The ACRE is a National Health and Medical Research Council Centre of Research Excellence, based at the University of Newcastle. Funding for the work was received from NSW Health's Clinical Cannabis Medicines Program.

Six prescribing guidance documents have been published with the following related to cancer treatment:

- Anorexia cachexia in advanced cancer
- Chemotherapy-induced nausea and vomiting
- Nausea in palliative care.

For details see:

<https://www.australiancannabinoidresearch.com.au/resources>

Cancer Voices NSW's feedback indicated that we had previously not taken a formal position on the use of medicinal cannabis (with any advocacy on the issue resulting from the efforts of individual members), but in 2017 adopted a position statement regarding the issue which supports the use of medicinal cannabis as another treatment option for those with cancer. The position statement is available on the CVN website.

<https://www.cancervoices.org.au/wp-content/uploads/2019/01/CVN-2019-Position-Statement-Medicinal-Cannabis-January-2019.pdf>

It is intended that the guidance documents will be reviewed and updated annually and/or as new evidence emerges as to the effectiveness of the use of medicinal cannabis in cancer treatment.

Access issues

More than 3,000 medicinal cannabis scripts were approved by the Therapeutic Goods Administration (TGA) in Australia from March 2018 to January 2019. However, some estimates suggest that up to 100,000 Australians are using medicinal cannabis illegally to self-medicate, often obtaining it, at significant cost, from overseas sources.

Patients and their supporters have a number of options to obtain medicinal cannabis:

- participation in a clinical trial. Such participation may, however, be limited by the difficulties of getting involved in a trial such as geographic location;

- obtaining a prescription from a doctor who is an Authorised Prescriber (AP). Becoming an AP involves a rigorous application process, obtaining approval from the TGA and endorsement from an ethics committee, checking for additional state or territory requirements, and providing the drug supplier with their authorisation. The Authorised Prescriber scheme has issued prescriptions to 473 patients as of early 2019;
- through the Special Access Scheme (SAS), whereby practitioners in most states and territories apply for special access to medicinal cannabis through Commonwealth and state approval. To date, over 3,500 applications have been approved under the Special Access Scheme.

Further action is needed to address legislative restrictions on the use of medicinal cannabis in Australia, resulting in unnecessarily complicated requirements for access. The Australian Greens had introduced a bill to the Australian Parliament in 2014 that would have allowed the creation of a single body in charge of approving, licensing, importing and exporting medicinal cannabis. However, the bill has now lapsed.

Since the election, given that it is unlikely that neither the Government nor the Opposition will progress legislation to ensure national consistency between the states and territories in a medicinal cannabis access program, Cancer Voices has written to Dr Richard Di Natale, leader of the Australian Greens and its spokesperson on health, indicating that we are:

...keen to learn how The Greens intend to progress action ... to ensure that equitable provisions are in place, where necessary through legislation, in relation to the implementation of nationally-consistent arrangements for access to medicinal cannabis. Cancer Voices is concerned at the delays that have occurred in the development of medicinal cannabis access programs and encourages The Greens to pursue the introduction of legislation to the new Parliament that will ensure equal access to medicinal cannabis across all states and territories.

Note: some of the information in this item has been obtained from the ABC website.

Murray McLachlan

Future of Cancer Survivorship – Evolution or Revolution?

Cancer Voices had a strong presence and a voice for people affected by cancer at the COSA Cancer Survivorship Conference, sold out weeks in advance and held in Sydney on 28-29 March 2019.

Members of the Organising Committee were Shirley Baxter, Deputy Chair of CVN and Chris Christensen, Chair of CVSA, with Executive Members, Lee Hunt, Lillian Lee and Deputy Chair Murray McLachlan co-chairing sessions. Lee and Lillian were also involved in session presentations.

Following three successful events in Adelaide, this was the inaugural conference to be held in Sydney by the Clinical Oncology Society of Australia (COSA), together with the Flinders Centre for Innovation in Cancer in Adelaide.

The provocative words in the title of **Evolution or Revolution** was apt and timely given the large numbers of people surviving cancer far longer than ever before. Living with and beyond cancer requires clear pathways and services for us to manage our health and wellbeing during treatment for cancer and beyond to live well.

The opening session, chaired by Prof. Bogda Koczwara and Murray McLachlan, featured Julie McCrossin AM and Dr. Ben Bravery, both of whom spoke openly and humorously about their cancer experiences, which set the tone for the entire conference of fresh and honest engagement around cancer issues.

Thought provoking and informative sessions were covered in areas such as *Managing Expectations after cancer, Conquering Stigma, Financial Toxicity, Carers, Beyond the Gym for people who don't wear lycra, Language and Cultural considerations.*

Lillian Leigh discussed how sensitive and mindful communication can conquer **stigma, marginalisation and fear**. Certain cancer types such as lung cancer face judgements by health professionals as well as the general public that can have a direct and adverse impact on a patient's outcome. Whilst Lillian acknowledged that it is human nature to have implicit biases, she also urged participants to stop and reflect on what they may be and how our physical and verbal language may communicate these biases.

Lee Hunt gave a personal account of the **financial toxicity** she has experienced since her first diagnosis of cancer 14 years ago. She also detailed the importance of the patient being informed of **treatment side**

effects, both early and late onset. Knowledge is vital to help the cancer patient manage side effects as they emerge. Her cancer treatments, given many years ago have led to ongoing chronic conditions and out of pocket expenses of over \$100,000. Whilst informed consent may have improved in more recent years, out of pocket expenses have not and are growing.

Today there is an improved focus in research on ways to manage cancer treatment side-effects. The continued involvement of consumers in cancer research will ensure that research continues to benefit the patient. **Cancer Voices calls for all treating clinicians to present written information on known treatment side-effects at the initial consultation with the patient**. This document will then become a reference for the patient and their carers throughout treatment and beyond, enabling them to determine when to seek medical support. It is most timely that this was an issue during the federal election. The draft NSQHS Standards User Guide for Medication Management in Cancer Care, including informed consent standards, was out for public review earlier this year. Lee, along with other CVN EC members, contributed to the Cancer Voices Australia response by providing feedback for the review.

Shirley Baxter and Chris Christensen chaired the **Carers Session** with Dr. Ben Britton a Clinical Health Psychologist with carers as panelists. Gail O'Brien, Tania Rice-Brading, Leslie Shears and Sana Qadar. Ben discussed the critical role of the carer and the need for their self-care in providing support. The panelists each gave their personal insights and perspectives having been a carer. There was a great deal to understand, whether it be a researcher or clinician, concerning the often overlooked role and needs of carers. **Cancer Voices calls for a wider awareness and understanding of the vital role of the carer by providing easy and timely access to support and comprehensive information for them** as in the link <https://www.cancercouncil.com.au/get-support/caring-for-someone-with-cancer/>

The Cancer Voices trademarked **Consumers Included (Ci)** logo was approved for use at the Conference given consumer participation in organising, chairing and presenting sessions.

Our thanks to COSA and the Flinders Centre in Adelaide for bringing this event to Sydney and to Cancer Council NSW, platinum sponsors of this event.

Shirley Baxter

Recent publications by cancer survivors

Through her personal experience with cancer, author and speaker, Jo Spicer realised that there were few resources to help her cope with the impact that cancer had on every area of her life.

Jo's new book, ***Survive and Thrive! How Cancer Saves Lives***, fills this gap in knowledge. It provides cancer patients and carers with inspirational stories and practical tips from 30 cancer survivors aged from 3 to 76 years, who have faced cancers including breast, prostate, lung, melanoma and blood cancers.

"This book will contribute to better outcomes and a more holistic approach to cancer treatment...contains wonderful practical advice for cancer patients, families and support persons." - *Dr Mark Bassett, Executive Director, Medical Services and Clinical Governance, Illawarra Shoalhaven Local Health District, NSW Health.*

Jo has also created a companion book, ***Ultimate Guide to Cancer Support for Patients and Caregivers***, a resource that contains everything you need to create a better cancer journey.

Books are available at www.jospicer.com and at all online and local bookstores.

Book Review: Curveballs - how to keep it together when life tries to tear you a new one.

Author: Emma Markezic. Harper Collins 2019.

An extraordinary book written by a young successful journalist and comedian following a diagnosis of cancer. The book that examines how trauma affects us in such different ways with practical ways to empower yourself whilst face to face with less than ideal situations in life.

A mix of memoir and self-help with many expert opinions and stories. This is a book about resilience, grief trauma, happiness and life.

2019 Patient Experience Symposium 29-30 April, ICC Sydney

It was pleasing to hear from Brad Hazzard, continuing Minister for Health, and Victor Dominello in the new position of Minister for Customer Service. Both stayed for some time which was encouraging.

NSW Health Secretary Elizabeth Koff summarised the change in approach from health professionals:

- What's the matter *with* you? → What matters *to* you?

Presentations covered a range of topics including:

Professor Helen Sanderson spoke of the experience of her mother at **end of life** – she was cared *for*, not cared *about*. She put forward the '1 page profile' as an excellent tool for patients to communicate with all health professionals as to what matters to them as a person. This has great benefit, and provides the opportunity to identify rural, regional and remote (RRR) patients easily so their appointments are given priority.

The Health Literacy Framework: A Guide to Action was launched by Kay de Ridder from the Clinical Excellence Commission.

<http://cec.health.nsw.gov.au/quality-improvement/people-and-culture/person-centred-care/health-literacy>

There are 4 priorities identified:

1. Patients, carers and families
2. Staff
3. Health System
4. Environment

Claudia Cresswell from Health Care Consumers Association ACT presented their First Impressions Project to improve **environmental health literacy**. They have developed an audit tool that they are happy to share, and if 'wayfinding' becomes a focus for CVN we could follow this up. I will be passing this on to Hunter New England Local Health District for the new Maitland Hospital that is in final design.

There was a presentation on a plain language program for public materials in one of the LHDs, using a readability counter, Patient Education Medical Assessment Tool (PEMAT) which scores and 'understandability' and 'actionability'. As someone who has worked in a technical field, it was a surprise to me that this was not common practice and therefore deemed worthy of a presentation.

Health literacy was a key focus of the symposium, and it was disappointing to learn that 60% of the population do not have a sufficient level of health literacy. There is much work to be done in this area.

Daniella Pfeiffer from Health Education Training Institute (HETI) presented on **Family Conferencing**. CVN can promote this service in NSW so that patients and consumers can ask for it when it is not offered.

Ensuring that family members who cannot be present are included through the use of technology is particularly useful for RRR families.

There was an inspiring presentation on the attributes of **patient-centred care** by Emma Gee, who had a stroke 13 years ago. She particularly highlighted the need for more support after the initial intense treatment, both emotionally and physically.

Jane Bradshaw, physiotherapist at Nepean Hospital, also spoke on **person-centred care** ie treating a person, not just a diagnosis. I learnt the value of Schwartz Rounds, the reflective practice that increases empathy in staff and decreases burnout.

Dr Abbey from Grafton Base Hospital spoke on **Patient Empowered Care (PEC)**, a market mechanism based on Nudge Theory. Patients empowered with knowledge can drive positive outcome/action by practitioners. His example was an increase of reporting to the GP within 3 days from <30% to >70% when patients get commitment from their specialist to make this report on time. The low adherence to this particular measure is of concern for all.

Ken Hillman made a very interesting presentation on the **Medicalisation of Dying**. His main thesis is that the RRS (Rapid Response System) in emergency departments do not identify patients as dying. The current medical system sees 'frail elderly' as a disease, but age-related frailty is not curable. He uses the CrISTAL tool, a clinical frailty score with 29 measures, to flag a discussion with specially trained nurses to empower people to make an acute care directive (ACD) that reflects their choices.

His call to action was to all present to demand better as consumers, as was done for birthing in the 60s.

Some statistics he presented:

- Over one-third of all hospital interventions are non-beneficial.
- >80% of patients suitable for palliative care are admitted to acute hospitals in their last year of life.
- 70% of people want to die at home; 70% of people die in acute hospitals.
- One-third of all RRS calls are for patients at the end of life. This is 15,000 calls in NSW/year
- 50% of older patients admitted to an ICU have died within one month of discharge.

The final presentation I attended was on **Advance Care Planning (ACP)** from the Clinical Nurse Coordinator at the Prince of Wales Hospital. Through a randomised controlled trial, they were able to prove that patients were more likely to develop an ACD when supported by a health professional. Potential patients were identified using the Supportive and Palliative Care Indicators Tool (SPICT) and they utilised the NSW Health booklet "*Making an Advance Care Directive*", which can be found here

<https://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf>

Overall the Symposium was well worth attending. There was also opportunity for networking during breaks including with Cancer Voices members and staff from Hunter New England Health.

Sarah Lukeman



Consumer Advocacy Training (CAT)

The first CAT course for 2019 was held at Cancer Council NSW Woolloomooloo NSW 28 February and 1 March 2019.

A very enthusiastic group of consumers (see photo) attended the two day training course ably presented by Carolyn Grenville and Katie Sheehan.

Cancer Voices NSW (CVN) has a spot on the agenda on Day 2. It is an opportunity for



a CVN rep to present a brief overview on who we are and what we do including our history, purpose, how we operate, our advocacy and consumer in research

programs. A short overview on our election strategy was timely given the approaching 23 March election.

Cancer Voices welcomes those who have joined following this course. We look forward to hearing about your ideas and issues for people affected by cancer.



Consumer Involvement in Research (CIR)

Cancer Voices Consumers in Research (CIR) program continues to grow due to the increasing acknowledgement of the value the cancer consumer brings to both cancer research projects and cancer related advisory committees. From December 2018 to July 2019, CVN has matched 93 consumers to 64 projects. This represents a growth of over 30% in the last four years. Several consumers have taken on the role of a Research Panel Consumer Advisor at research institutions. In this role the consumer works with different research teams across a range of research projects. Others work on Consumer Review Panels and are engaged with a small team of researchers to ensure valid research direction.

We have also been asked to be involved in a Patient-led Study led by a researcher from the United Kingdom, who was the first patient to receive a research grant from the Bowel Disease Research Foundation. CVN Executive Committee members are involved with many ongoing cancer committees and organisations and continue to ensure that consumers are represented in every aspect of cancer research and planning. These consumer roles continue for several years and add to the impact of the CIR program.

The current projects are diverse and look at a variety of cancers and areas to improve both quality of life and new ways to control cancer. Consumers are involved with activities such as 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, and best practice guidelines. There have been several project requests from interstate universities and institutions. For these projects the consumer can engage with the research team via teleconference or Skype.

The Cancer Institute NSW has partnered with Cancer Council NSW to fund two landmark cancer research programs. Several of our consumers are working with researchers at the ACRF Image X Institute which received one of these grants of \$3.75M to support their translational research work for 5 years. The funding will allow the ACRF Image X Institute to foster stronger collaborations with partnering hospitals and industry, opening an accelerated path from discovery phase

through to technologies used in clinical practice. Tumour tracking systems make imaging and radiation therapy more precise and safer for patients. The improvements to targeted radiation therapy, reducing toxicity to surrounding tissue and organs, will go on to have an impact on millions of lives around the world.

Cancer Voices executive members have been asked to talk about the CIR program and the value consumers bring to cancer research. Recent presentations included at a seminar to PHD Health Research students at Sydney University. Discussion included how consumers relate to research; the benefits of CIR for the researcher, consumer and the community; how the program operates, and strategies for involving the consumer in lab-based research. Although a few of the students were involved with cancer research, several were working in different health areas. Avenues for finding a consumer for non cancer-based research were workshopped. A Q and A session which enabled clarification and suggestions to support future consumer engagement followed. The feedback from the session was positive with an increased awareness of how their research will be enhanced by including consumer engagement.

Lee Hunt

Cancer Voices also presented at the **Public Involvement in Health Service Research International Symposium**, Faculty of Health Sciences, University of Sydney. It was all around consumer involvement and consumer led research and presented some great initiatives from across the wider health continuum.

The program comprised some 44 presentations presented in parallel sessions. Cancer Voices was the only cancer consumer group present and there was certainly interest in our CIR program, with many attendees envious of what we have achieved and keen to emulate our success.

Elisabeth Kochman

Consumers in Research Training

Would you like to become involved with CIR?

The Consumers in Research Training Program comprises four online modules which need to be completed before attending a half-day workshop to be held at Sydney office of the Cancer Council NSW (CCNSW).

Training for 2019 will be held on 20 September. This training provides participants with an insight into the types of cancer research, the stages of research and the funding cycles, along with what is expected of the consumer.

The modules can be accessed at

<https://cancercouncil.litmos.com.au/online-courses/>

Further information:

<https://research.cmail19.com/t/ViewEmail/r/968D2F9C92FC3AEC2540EF23F30FEDED/39DA4326CB003668942A2DF08F503B7C>

Promotion of the CIR program

Cancer Council NSW (CCNSW) has published a three-part blog series on the Consumer Involvement in Research program. [Part 1](#) is about their Consumer Review Panel, [Part 2](#) is about the Consumers in Research workshop, and Part 3 will be about the researcher's perspective on consumer involvement and will feature an interview with CCNSW's researcher A/Prof Natalie Taylor

Funded Research Projects

Following are links to research projects that have been awarded funding by both Cancer Council NSW and Cure Cancer Australia for 2019. Evidence of consumer engagement throughout the project is a requirement for receipt of this funding.

CCNSW research recipients for 2019: For details of the 13 innovative cancer research projects awarded grants <https://www.cancercouncil.com.au/blog/the-13-innovative-cancer-research-projects-we-chose-for-grants-in-2019/>

Cure Cancer Australia research recipients for 2019: Details at <https://www.curecancer.com.au/our-researchers>

Prof. Paul Keall, one of the above recipients, was also granted the \$3.74m Cancer Institute NSW Translation Grant.

A research handbook for patient and public involvement by researchers from the Manchester University Press Open Access content

"This handbook is written for patients and members of the public who want to understand more about approaches, methods and language used by health services researchers" (from the website, see link below)

This is downloadable in chapter format

<https://www.manchesteropenhive.com/view/9781526136527/9781526136527.xml>

The inaugural Sally Crossing AM Award for an Outstanding Achievement in Cancer Research

This inaugural award was announced at the 2019 annual Cancer Council NSW Research Awards Night. 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.

Entries were invited from researchers who have received funding from Cancer Council NSW in the last 10 years. A very humble and surprised [Professor Murray Norris AM](#) from the Children's Cancer Institute was this year's recipient of the \$50,000 award. Alex Crossing and Peter Crossing presented the award.

Read more at <https://www.cancercouncil.com.au/blog/celebrating-outstanding-work-for-children-with-leukaemia/>

This award was made possible through the generosity of the Belalberi Foundation, a foundation established by the family of the late Sally Crossing AM (1946-2016). Sally was a pioneer and tireless advocate for patient-centred medicine, and the first consumer appointed to the Cancer Council Board. She advocated strongly and continuously for training in consumer advocacy and for the inclusion of consumers in research.

Cancer Council NSW and Cancer Voices NSW acknowledge the extraordinary support of the Belalberi Foundation and the Crossing family in conferring this award.

PACER/SPH Travel grants for patients and caregivers involved in research

The Patient-centred research (PACER) Network and the Sydney School of Public Health (SPH) travel grant provides support for patients/caregivers for domestic (within Australia/New Zealand) and international travel for research-related activities (including but limited to scientific conferences, research workshops, research fieldwork). **Applications are now open and will close 15th September 2019.**

Background

Many healthcare organisations are increasing their focus on delivering patient-centred care, which is one of the core academic areas of The University of Sydney. The **PACER network**, a joint initiative of The University of Sydney, Kids Research at The Children’s Hospital at Westmead, Westmead Hospital, and the Westmead Institute for Medical Research, was launched in 2018 to facilitate knowledge exchange, collaboration, and

innovation in conducting and implementing patient-centred research. The PACER network also provides training and opportunities to strengthen patient involvement in research.

Eligibility

Applicants must be patients or caregivers who are registered with the PACER network (<http://pacernetwork.org.au/join/>) and are involved in health research activities related to a disease, disability or health condition. Applicants must be residing in Australia.

All applications must be submitted using the online form at <http://pacernetwork.org.au/travel-grant/> by COB 15th September 2019.

If you have any questions, please contact Amanda Baumgart (Amanda.baumgart@sydney.edu.au) on behalf the PACER Advisory Group and Coordinating Committee.



Consumers Included – a logo “seal of approval”

A Cancer Voices initiative, launched in late April 2016, and Trademarked in December 2017.

The purpose of the Consumers Included (Ci) logo is to encourage and acknowledge organisations which enable consumers to participate in conferences, meetings and other events which are of interest to them – and which will benefit from their involvement.

Further information can be found on the Consumers Included website at <http://consumersincluded.wordpress.com/> which advises applicants on how to apply for its use, as well as listing those who have been awarded approval to use the logo.

If you have any questions, please contact us via the email address highlighted below.



Consumers Included – Seal of Approval – Trademarked 2017

For more information contact: info@consumersincluded.org.au

and the Ci tab on Cancer Voices Australia’s website www.cancervoicesaustralia.org.au

Rural Australia

Radiation Therapy for Rural Australia

Cancer patients in rural Australia deserve access to high quality cancer care and access should be equivalent to city patients. As radiation therapy is needed for approximately 50 per cent of cancer patients, those in rural, regional and remote areas must be able to access a centre within a reasonable distance to receive daily treatment. They deserve the same choice of treatment options as cancer patients in metropolitan areas.

Cancer Voices NSW supported the community of Dubbo in its successful campaign to address the issue of poor access to cancer services. The federal and state governments have provided funding for a cancer centre at Dubbo Hospital. The centre will have: a 15-chair chemotherapy unit: chemotherapy using remote video assistance at distant sites such as Coonabarabran (*see following article*) and potentially Walgett, Bourke and Cobar; a linear accelerator for radiotherapy; a PET-CT scanner for better diagnosis; a clinical trials unit; cutting edge treatments which are presently only available in Sydney; and possibly a nuclear medicine service and orthovoltage radiotherapy (which uses superficial radiation for skin cancers to avoid surgery).

Members of Parliament and candidates in this year's federal election were asked to support an advocacy campaign focusing on the lack of radiation therapy services in other regional centres. In May the Radiation Therapy Advisory Group (RTAG) launched a campaign calling for the next federal government to invest in radiation therapy for regional Australia and address the clear underuse of radiation therapy in 13 identified locations across country communities.

There was bipartisan support, with both the Government and Opposition committed to providing funding for radiation therapy treatment for rural and regional Australia. The coalition government has committed to investing \$63.4 million to expand cancer treatment capacity through new radiation therapy services in the 13 regional locations. They will work with key stakeholders to ensure that the investment is well targeted to support regional populations centres that can service their surrounding areas. This funding will provide greater access, help and support for people fighting cancer.

The indisputable fact is only one in three Australian cancer patients today receives radiation therapy as part of their cancer treatment program. This is in stark contrast to Europe and North America, where one in

two cancer patients will receive radiation therapy. A significant problem in Australia is lack of access, and this is most obvious in many country towns.

Geoff, a consumer who spoke at the campaign launch, described the physical toll of driving for more than two hours each way for his daily radiation therapy treatments. The travelling, on top of the 'all-consuming' treatment, was demanding, mentally and even socially. Physically it was 'utterly exhausting'.

Research has revealed that for patients who need to travel long distances to access cancer treatment, some will make the decision not to have treatment. People with cancer in regional centres are up to 35 per cent more likely to die within five years of diagnosis than those living in metropolitan areas. For indigenous Australians, those outcomes are worse.

As well as the need for more radiation centres in rural Australia, there is underfunded support by state governments for transport and accommodation for rural and remote patients to access distant centres. Travel and accommodation are important considerations when travelling for medical treatment. CVN members raised this issue with both Government and Opposition representatives during meetings with them as part of the CVN 2019 Election Strategy along with the fact that participation in clinical trials is currently excluded from the NSW Isolated Transport Accommodation and Assistance Scheme (IPTAAS). CVN will continue to pursue this inequity with government representatives.

Patient assisted travel schemes offer support for people who meet eligibility requirements and are managed individually by states and territories. In NSW under IPTAAS the accommodation subsidy is \$43 per night for a single room (\$60 for a double) and 19 cents per kilometre rebate for a private vehicle. The state travel subsidy scheme is inherently inequitable for rural, regional and remote Australians as their out-of-pocket expenditure can be prohibitive for extended cancer treatment. Subsidies paid out need to reflect the true costs incurred for travel and accommodation and include access to clinical trials.

Lee Hunt

Telehealth for NSW – delivery of chemotherapy treatment

On 28 June ABC News and ABC 7.30 ran a feature on Telehealth in NSW. In 2017 Dubbo Base Hospital began a trial with Coonabarabran to deliver chemotherapy treatment using *remote video-assisted chemotherapy*. This is now standard care. It is saving time on the road and saving and prolonging life. They are now considering expansion to places like Cobar and Walgett.

Whilst this is a first for NSW, this service has already been rolled out across Queensland. This is all based on the pioneering work of Professor Sabe Sabesan in far north QLD.

The COSA Teletrials Consortium (of which CVN is a member) is also based on his work.

Prof Sabesan, who is based in Townsville has been described as having a 750,000 sq km clinic in far north QLD due to Telehealth. Cancer Voices urges the NSW Government to provide the necessary funding to replicate the Queensland scenario and thereby enabling those in rural and remote areas of NSW to be able to choose treatment options without the stress of travelling long distances.

Elisabeth Kochman

The Voices being heard

Meetings

- 22 January; Lymphoedema Action Alliance teleconference
- 24 January; CCNSW Research; CVN Workshop planning
- 5 February; RTAG - Radiation Therapy Advisory Group meeting
- 6 February; Steve Allen 3-Degrees
- 8 February; Targeting Cancer - RANZCR Meeting
- 12 February; RANZCR Standards Working Party teleconference
- 14 February; RTAG Meeting
- 15 February; CVN AGM & Strategic Planning Workshop
- 18 February; Cancer Council Australia teleconference
- 19 February; Rare Cancers Aust teleconference
- 20 February; NSW Health
- 28 February; RANZCR Faculty of Radiation Oncology Planning
- 1 March, RANZCR Faculty of Radiation Oncology Annual meetings
- 4 March, Cancer Institute NSW, Quarterly meeting
- 6 March, Dementia Research (teleconference)
- 6 March; Rare Cancers Aust teleconference
- 6 March; RANZCR Interventional Radiology Committee
- 27 March; COSA Teletrials Consortium teleconference
- 2 April; Lymphoedema Action Alliance
- 8 April; RTAG meeting
- 9 April; Cancer Australia Intercollegiate Advisory Group
- 10 April; Cancer Council NSW, Quarterly meeting
- 11 April; Research4Me
- 13 May; COSA Teletrials Consortium
- 14 May; Cancer Institute NSW, Cancer Control in NSW briefing
- 17 May; Health Consumers NSW; CVN Executive Committee meeting
- 20 May; Concord Survivorship Centre
- 27 May; Cancer Voices SA teleconference
- 11 June; Cancer Australia; Early Breast Cancer Expert Working Group
- 17 June; Cancer Institute NSW Quarterly meeting
- 19 June; Cancer Council Australia; Rare and Less Common Cancers resource project

- 28 June; FRO Meetings Brisbane
- 4 July, Cancer Council NSW, Quarterly meeting
- 16 July, RTAG meeting
- 16 July; Lymphoedema Action Alliance
- 19 July; Out of Pocket Working Group; Melbourne
- 24 July; CVN EC meeting

Conferences / Forums / Events

- 14 February; Mailchimp training
- 15 February; CVN EC Strategic Planning Workshop
- 18 February; CCNSW Candidate Forum Mosman (Note: 1 of 17 held around the state prior to the state election)
- 20 February; Uni of Sydney, CIR Presentation for PHD Students
- 21 February; Uni of Sydney, CVN / CIR presentation at the Public Involvement in Health Service Research International Symposium
- 25 February; Launch - Radiation Therapy for Regional Australia, Newcastle
- 1 March, Hunter New England (HNE) Cancer Network Forum
- 1-2 March, CCNSW Consumer Advocacy Training (CAT)
- 14 March; Cancer Council NSW Research Awards
- 28-29 March; COSA Survivorship Conference
- 29-30 April; 2019 Patient Experience Symposium
- 2-3 May; Inaugural Australian Patient Network Symposium
- 17 May; CVN EC Strategic Planning Workshop
- 24 May; Admiralty House: Farewell for Helen Zorbas
- 30 May; Cancer Australia; Farewell for Helen Zorbas
- 23-24 July; Health Summit, Canberra

Submissions / Feedback

- February; MBS Colorectal Surgical Response (Dept of Health)
- May; Draft NSQHS Standards User Guide for Medication Management in Cancer Care
- June; Cancer Australia: Review of an EBC Survivorship resource

Cancer Council NSW Update

Farewell and thank you

As a result of recent changes in the Policy and Advocacy (P&A) Unit of Cancer Council NSW, three long standing members of the P&A Unit have elected not to stay on. Carolyn Grenville, Advocacy Network Development Officer, Katie Sheehan, Project Coordinator and Bernadette Roberts, Senior Policy Analyst, all finished up on 27 June.

Cancer Voices has enjoyed a strong and close working relationship with them over many years. We would like to thank them all for the enormous contribution that they have made in the interests of those affected by cancer. We wish them well in their future endeavours. **Elisabeth Kochman**

Enrich Survivorship Program is a free exercise and nutrition program for cancer survivors. It is an eight week program comprising a two hour session one day a week. For further details

<https://www.cancercouncil.com.au/enrich/>

Cancer Council Helpline

Talk to a qualified health professional

Call 13 11 20

Monday to Friday 9am – 5pm

Cancer Institute NSW Update

Cancer control in NSW - The latest information about cancer control in NSW for 2018

This statewide report presents the latest information about cancer control in NSW. This information is collected and reported each year as a part of the Cancer Institute NSW [Reporting for Better Cancer Outcomes \(RBCO\) Program](#).

Through the RBCO program, the Institute collects and analyses data from across the state every year. This allows them to see what progress is being made in cancer control. This information is shared with key health organisations so they can identify opportunities for improvement at a local level.

Reputable and reliable information for people affected by cancer

[Patient Information](#) is a website to help people affected by cancer to find trusted and reliable information that is relevant to their situation, including diagnosis, treatment and possible side effects.

Patient information gives key messages and information that is easy to read. It is presented in small chunks to make it less overwhelming. There are links to further information that have been reviewed and recommended. The links take the user to the relevant page of what they were reading – making it easier to access. Other features on Patient Information includes checklists with tips and questions to ask.

All content that is presented on Patient Information is reviewed by consumers and clinicians and comments are collated and reviewed.

A link to the site can be found on the Cancer Institute NSW website or at <https://patients.cancer.nsw.gov.au/>

If you would like to be involved and contribute to the reviewing process please contact us at info@cancervoices.org.au and we will put you in touch.

Releases from Cancer Australia

New era of insights with release of survival by stage at diagnosis data

Cancer Australia has analysed national data on survival by stage at diagnosis for the top five high incidence cancers – female breast, colorectal, lung, melanoma, and prostate.

The release of the data on survival by stage at diagnosis marks a significant advance in the reporting of national cancer information. The new data allows us to examine how survival varies depending on the stage of cancer at diagnosis, and to better understand differences across sociodemographic groups.

These national data are a result of Cancer Australia's leadership and collaboration with all the state and

territory population-based cancer registries and the Australian Institute of Health and Welfare.

To access the data, visit ncci.canceraustralia.gov.au

National data released on stage at diagnosis and survival for childhood cancers

Cancer Australia has released updated [national data on childhood \(paediatric\) cancer stage at diagnosis and survival for the period of 2006-2014](#), using more detailed staging systems intended for well-resourced cancer registries. These data cover sixteen major cancer types, which represent approximately three-quarters of all childhood cancers diagnosed in Australia and other high-income countries.

The release of these data on stage at diagnosis for childhood cancers marks a significant advance in the reporting of national cancer data.

These data, collected through collaboration between Cancer Australia and the Cancer Council Queensland and with involvement of all states and territories and major paediatric hospitals, can be viewed by tumour type, and provides information on [stage distribution](#) as well as [5-year survival by stage at diagnosis](#).

Visit childrenscancer.canceraustralia.gov.au.

It's ok to talk about cancer – Yarn for Life

Cancer Australia has launched [Yarn for Life](#), a new initiative aiming to encourage and normalise discussion about cancer in Aboriginal and Torres Strait Islander communities. To reduce feelings of shame and fear associated with cancer, *Yarn for Life* shares 3 personal experiences of cancer from Indigenous Australians which are stories of hope, courage and survivorship. For more information visit yarnforlife.com.au The *Yarn for Life* initiative is supported by [consumer resources](#) which outline what patients should expect at all points on the cancer pathway.

For more information, including talking about cancer, seeing your health worker and keeping on top of your health, visit yarnforlife.com.au.

Cancer Statistics

In May, Cancer Australia published up to date statistics on **31 tumour types in Australia**, including data on Aboriginal and Torres Strait Islander people, on its website.

Farewell to Dr Helen Zorbas

Dr Helen Zorbas, who has been CEO of Cancer Australia for 9 years, decided that she would not seek reappointment to the position. Dr Zorbas has been well known to Cancer Voices. Many of us have known her since the early days of the National Breast Cancer Centre (NBCC) which then became National Breast and Ovarian Centre (NBOCC) and finally merged with Cancer Australia. Helen Zorbas has always been very supportive of consumer inclusion and involvement at all levels.

Through her passion, vision and leadership, she has done and given so much, both as a clinician and a leader in cancer control in Australia over many years, all with her own unique style, composure and presence.

Cancer Voices attended two farewell events to acknowledge Helen Zorbas' enormous contribution.

We wish her well in her future endeavours.

New CEO of Cancer Australia

Cancer Voices welcomes Professor Dorothy Keefe as the new CEO of Cancer Australia effective July 2019. Her appointment is for three years.

Professor Keefe is from South Australia and has held many senior roles including at the University of Adelaide, Royal Adelaide Hospital and as interim Medical Director of SA Cancer Service along with many national representative roles.

Professor Keefe's experience is not only as a medical oncologist but also in the toxicity of cancer treatment, cancer patient advocacy and in healthcare reform.

Professor Keefe has been a member of the Cancer Australia Advisory Council since 2015. Outgoing CEO, Dr Zorbas said "Professor Keefe's breadth of experience and long-standing association with Cancer Australia will ensure a successful transition and a strong foundation for Cancer Australia's continued national leadership role in cancer control into the future."

This appointment was announced by Health Minister Greg Hunt in March this year.

Note: Some of the above is from the CA website

Elisabeth Kochman

Cancer Australia is the Australian Government's national agency in cancer control. It was established in 2006 to benefit all Australians affected by cancer, and their families and carers. Cancer Australia aims to reduce the impact of cancer, address disparities and improve outcomes for people affected by cancer by leading and coordinating national, evidence-based interventions across the continuum of care.

Government relations

Following the May Federal election, CVA has sent congratulatory letters to the reappointed Minister for Health, Greg Hunt, newly appointed Shadow Minister for Health, Chris Bowen, and the leader of the Australian Greens and health spokesperson, Dr Richard Di Natale. Minister Hunt has since responded. CVA is currently in the process of arranging a meeting with the Minister's advisors. Such contact, at both state and federal level, is extremely important in establishing a base from which to contribute to decision making at the government policy and program level.

We would also like to acknowledge Catherine King for her commitment to health during her long tenure as Shadow Minister for Health in the previous government.

Health Summit, Canberra

CVA has been invited to participate in a two day Health Summit in late July. Participating organisations from across the broader health continuum will come together *"to discuss and debate important reforms that put Australians at the heart of health policy making"* and to identify deliverable policy solutions. We will certainly have more to share with you in our next edition.

Australian Government Response to the Senate Select Committee Inquiry report: Funding for Research into Cancers with Low Survival Rates

To view full report
<https://www.health.gov.au/internet/main/publishing.n>

[sf/Content/gov-response-funding-for-research-into-cancers-with-low-survival-rates](https://www.health.gov.au/content/gov-response-funding-for-research-into-cancers-with-low-survival-rates)

Australian Cancer Consumer Network (ACCN)

The ACCN was established in 2014 and brings cancer consumers group together to share information, experiences and issues. It currently numbers close to 30 groups covering many specific cancers and some generic cancer groups. It is convened by Dan Kent for CVA. Dan regularly circulates information of mutual interest. Recently each member organisation has been contacted inviting them to update their organisation's details for the website directory.

For more information
<https://www.cancervoicesaustralia.org/accn/>

Cancer Council Australia Rare and Less Common Cancers (RLCCs) resource project has resumed following the appointment of a new project officer. A RLCCs booklet will be produced and the following RLCCs have been identified for development of factsheets: Adenoid cystic carcinoma (AdCC); Appendix & pseudomyxoma peritonei (PMP); Gall bladder & biliary tract; Neuroendocrine tumours (NETs; Ocular melanoma; Penile; Small bowel; Soft tissue sarcoma; Urinary tract urothelial carcinoma (UTUC). Consumers have been involved, including in focus groups and interviews and will also be involved in the review of the new resources. Cancer Voices is a member of the steering committee. This project is being funded by Cancer Australia.

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

THANKS to the Team who bring you this Newsletter:

Kathryn Leaney for formatting, Sharon Pannewitz for database management, Murray McLachlan for proof reading and Elisabeth Kochman as compiler & Editor & all our contributors. Special thanks to Geoff Vass for technical support.

We hope you find it interesting, even inspiring! Let us know about any other advocacy issues you think we should feature and/or work on, and if you would like to help.

REMEMBER All our newsletters are available via our website.