

Message to Members

Welcome to 2018 and the *seventieth edition* of the Cancer Voices Newsletter - quite a significant milestone in our history! All our newsletters can be found on our website and are also registered with the National Library of Australia so that this important history is not lost.

We were delighted to finish 2017 with the registration of the trademark for our logo **Consumers Included (Ci)**. This initiative was launched in April 2016 based on the overseas initiative "Patients Included". Its potential use in spreading the Cancer Voices message is enormous. We will certainly keep you advised of our plans and progress.

We didn't seem to stop for very long over the break. Commitments were well under way in January. Several of the Cancer Voices Executive Committee joined other consumers to participate in focus groups on **Survivorship – Patient Reported Outcomes** in mid-January. Shirley Baxter provides further details on Page 6.

Conferences: February saw Cancer Voices representation at two conferences. Cancer Voices NSW and SA attended the two day **Peter Mac Survivorship Conference in Melbourne** (see photo) with CVSA having a poster displayed. Shirley Baxter provides an overview on Page 10. A link to the poster can be found on Page 11.

The Australasian Oncology Summit was held in Brisbane in late February. Lee Hunt provides details

of new oncology care management software which was demonstrated at the conference on Page 11.

CVN AGM and Report 2017: Our annual report highlighting the year that was, was presented at our AGM on 16 February. For details see Page 13. The report can also be found on our website. Our 2018 Executive Committee is listed on Page 3. A big thank you to those EC members who are continuing on.

NSW Updates: Both the Cancer Council NSW and the Cancer Institute NSW will continue to provide

overviews on their respective programs, initiatives and services in each newsletter. Details are on Page 9.

2018 is shaping up as another year of much activity with our advocacy work particularly with our state election in March 2019.



L – R: Imogen Ramsay (PhD student / presenter), Julie Marker (CVSA), Shirley Baxter (CVN)

We do value your feedback and are always pleased to hear from our members and readers. Please let us know what you think about issues that we are pursuing and certainly let us know if we have missed something important.

We wish you all the very best for 2018 and will continue to do our best in the interests of those affected by cancer.

**Elisabeth Kochman and
the Cancer Voices Executive Team**

Cancer Voices SA

For news from our colleagues in SA: www.cancervoicessa.org.au

For CVSA newsletters: <https://www.cancervoicessa.org.au/information/newsletters-documents>

CVN Notice Board

Consumer Advocacy Training – 2018

Connect with like-minded people and develop your advocacy skills.

Friday 4th and Saturday 5th May, 2018

Courses are open to CVN and community members. Visit the Cancer Council's website for dates and locations.

The two day workshop provides skills and tools to help you make a difference, and will equip you to:

- *Become active and effective advocates for better cancer policies and services*
- *Approach consumer representative work with more confidence*
- *Understand how “the system” works, and how you can influence decision-makers.*

Apply online: http://www.canact.com.au/advocacy_training

Phone Carolyn: (02) 9334 1855 or Marion (02) 9334 1859 Email: advocacy@nswcc.org.au

NB: Mention you are a Cancer Voices member for automatic registration.

2018 PATIENT EXPERIENCE SYMPOSIUM

Monday 9 April – Tuesday 10 April
Hilton Sydney
488 George Street, Sydney NSW
#PEX2018



Cancer Institute NSW Patient Symposium <https://www.cancerinstitute.org.au/about-us/events/upcoming-events/2018-patient-experience-symposium>

2018 Public Seminar Program at the Garvan

Registration is free.

<https://www.garvan.org.au/foundation/news-events/public-events/public-seminars/>

Past seminars can be accessed via their [YouTube channel](#).

Brain Cancer Action Month – May

- Cure Brain Cancer Foundation Ball, Sydney, Saturday 5 May
- Mark Hughes Foundation, Newcastle Forum, Sunday 6 May
- NSWOG-NO Brain Cancer Action Forum, Sydney, 24 May



Watch out for a new publication due for release in June 2018:
Successful Cancer Research - A Resource Guide

<https://www.elsevier.com/books/keys-to-running-successful-research-projects/christian/978-0-12-813134-3>



CVN Committee News

Cancer Voices Annual General Meeting was held 16 February in the Woolley Room, Level 1 SMSA Building, 280 Pitt Street Sydney. We were delighted to have Peter Crossing AM join us. He also fulfilled the role as returning officer. Our 2017 Annual Report is published in this newsletter (see Page 13) and is also available on our website.

Your Executive Committee (EC) for 2018 is as follows:

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, Peter Brown, Roberta Higginson, Jan Mumford, Susan Pitt, Sarah Lukeman
Advisor:	David Campbell

David Campbell and Elaine George did not re-nominate for 2018. Both remain members of CV. We are grateful to David for his contributions since 2015 which included instigation of our very successful survey of researchers and consumers resulting in the CIR Evaluation Study Report and poster (published Aug 2016). David changed the way we approached our priorities by rationalising and recategorising them in 2016. He also provided input to our workshop in February. David will remain a "friend" to CVN and has taken on the role as Advisor.

Elaine is needing to concentrate on her well-being and treatment. We thank her for her contribution during 2017 and acknowledge her effort in organising the inaugural Flashmob Dance to create awareness of metastatic breast cancer. She still wishes to contribute in the area of metastatic disease.

CVN Strategic Workshop:

Following our AGM on 16 February, the EC conducted a "think tank" workshop. This was facilitated by fellow CVN member Kathryn Leaney. Kathryn's knowledge and understanding of CVN coupled with her professional skills of facilitator and trainer enabled her to provide great focus and direction. We were delighted with what we achieved in the time available. Kathryn has provided us with a valuable summary of our session including an action plan of what we need to do that will certainly keep us busy. We will keep you informed as we progress with this plan.

Thank you Kathryn: CVN is very grateful for the preparation, the direction on the day and valuable summary that we now have to assist us going forward.

Reconnection: I was delighted to once again touch base with Jane Cruickshank, one of the founders of CVN and our second Chair. We met up again when Jane attended the COSA Public Consumer Forum last November and I was able to re/introduce her to some current EC members. I worked with Jane when I joined the EC and always admired her ethics and dedication to getting the job done. A great mentor.

Thank you to Health Consumers NSW (HCNSW):

We will continue to meet at the offices of HCNSW for a second year. As stated last year, it is a very welcoming environment as well as a very convenient city location. This arrangement has also helped foster a closer relationship between our two organisations. At the HCNSW AGM in December there were tributes to Sally Crossing where her work with Betty Johnson to establish HCNSW in 2012 was acknowledged along with her wider advocacy work. CVN was profiled as a group member in their annual report which can be found at http://www.hcnsw.org.au/data/HCNSW-AnnualReport_2017_ONLINE.pdf



CVN Advocacy Updates

Lymphoedema Action for NSW

The Lymphoedema Action Alliance (LAA) (of which CVN is a member) had its first meeting for 2018 on 6 February.

Representatives of the LAA met with Emma Chapman from NSW Health Minister's office in November 2017.

It was a very positive meeting where current and previous asks were raised including:

- To find out the current number and locations of full time equivalent public lymphoedema therapists funded by NSW Health to provide lymphoedema services in Local Health Districts.

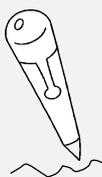
- To make this list of lymphoedema services available on a central website so that patients can access this information, and health professionals can appropriately refer people for treatment.
- More public lymphoedema therapists funded.
- A meeting with the NSW Health Minister in the near future to further discuss barriers and potential strategies for increasing access to public lymphoedema treatment in the NSW Health system, to improve outcomes for people living with lymphoedema across NSW.
- It has been suggested that the Health Minister support the ACI Chronic Care Network to launch the new document, *'Key principles of care for people living with, or at risk of, lymphoedema'*, which is nearing completion and will provide an exciting opportunity for improvements in lymphoedema care.

Saving Life 2019 – Collecting stories

Cancer Council NSW has recently committed to campaigning for **more support for people with lymphoedema**, in the lead up to the NSW state election in March 2019. CCNSW will of course be working alongside the Lymphoedema Action Alliance throughout the campaign.

One of the **key components of the Saving Life 2019 campaign will be the use of story**. We will be using stories to support our campaign and influence the views of candidates, political parties and the next NSW Government across social media and local media; local candidate and community forums; when meeting with local MPs and other decision makers, and in written materials.

We would love to hear from people who have an experience, positive or negative, of accessing public treatment for their lymphoedema.



If you have a story you would like to tell, please complete the enclosed template and email to Carolyn Grenville, carolyng@nswcc.org.au or call 9334 1855 for more information.

Insurance, cancer and the Royal Commission

People affected by cancer continue to face challenges when accessing insurance. Cancer Voices NSW has recently received an update from Legal Aid NSW that a report on this issue is close to publication. The report will release the results of their online survey.

In the United Kingdom, the Financial Conduct Authority is currently investigating this issue, and CVN is anticipating that it will release its findings soon.

CVN encourages members to consider making submissions to the **Royal Commission into Misconduct of Banking, Superannuation and Financial Services**. Anyone with problems accessing or claiming on insurance policies (e.g. travel insurance and life insurance) because of cancer should consider filling out the 3-page online form (royalcommissionwebform.lawinorder.com.au).

Simply by sharing your story with the Royal Commission, you can powerfully advocate for better access to insurance for all people affected by cancer. For more information, visit:

financialservices.royalcommission.gov.au/Public-submissions.

Palliative care in rural and regional areas

The NSW Government announced increased palliative care resources for rural and regional areas in early December last year. As part of its wider palliative care funding package announced in the 2017-2018 state budget, the following local health districts will receive funding for a palliative care specialist position:

- Central Coast
- Far West
- Hunter New England
- Illawarra Shoalhaven
- Mid North Coast
- Murrumbidgee
- Northern NSW
- Southern NSW
- Western NSW

Further, both Central Coast and Illawarra Shoalhaven LHDs will receive an additional specialist position.

Parliamentary Secretary for Health Leslie Williams, who has a nursing background, made the announcement at Dubbo Base Hospital on 4 December 2017, saying that 'The NSW Government is committed to investing in

palliative care right across the health system so that patients have real choices in the care they receive at the end of their life’.

Murray McLachlan

Assisted Dying Legislation

Following the narrow defeat (by twenty votes to nineteen) of the *Voluntary Assisted Dying Bill* in the NSW Legislative Council on 16 November 2017, it is not expected that the issue will be considered by the NSW Parliament until after the next state election in March 2019.

There have however been developments in other jurisdictions that will, in time, have an effect on how the introduction of provisions for patients with cancer in NSW to have greater choice in treatment and end-of-life care options are likely to come about.

These developments include:

- Recent research by the Roy Morgan company that indicates 87% of Australians (up from 69% in May 1996) support patients being allowed to die when there is no chance of recovery and they are experiencing unrelievable suffering. Further, 85% (up 11% from May 1996) support allowing a doctor to administer a lethal dose when a patient has no chance of recovery and requests that lethal dose.
- The Victorian Parliament passed its equivalent legislation on 29 November 2017, with its assisted dying provisions (which are however not directly comparable to those in the defeated NSW bill) expected to be in place by mid-2019.
- The Premier of Western Australia, Mark McGowan, has indicated that he expects the parliament to consider legislation at some point during 2018.
- The Legislative Assembly in the Australian Capital Territory has called for submissions to a Select Committee on End of Life Choices which is due to present its report by 29 November 2018.
- In New Zealand, the *End of Life Choice Bill* is being considered by the NZ Justice Select Committee, with the public being able, for the first time, to submit its opinions on the issue. The recently-elected Prime Minister, Jacinda Ardern, has expressed her support for the bill, on the basis of the need for improved patient choice.

- The leader of the Australian Greens, Dr Richard de Natale has, following passage of the Victorian Bill, announced that he will pursue legislation at the federal level that would provide a framework for each state to pursue its own legislation, based on the Victorian model.

The Executive Committee will continue to monitor state and national developments, particularly in the context of the NSW state election, and the federal election that is likely to be held in 2019, given that the best outcome for patients who are dying would be legislation that is nationally uniform to provide fair and consistent end-of-life choices across the country.

Murray McLachlan

New resources from Cancer Australia

Do read the new guide *Finding the Words* – starting a conversation when your cancer has progressed to assist with the transition to palliative care. Palliative care helps people live as well as possible, relieves symptoms and improves day to day life - well before end of life. <https://canceraustralia.gov.au/about-us/news/support-transition-palliative-care-people-metastatic-cancer>



See the new Cancer Australia web site <https://childrenscancer.canceraustralia.gov.au/>

Legislative Council Select Committee on off-protocol prescribing of chemotherapy in New South Wales update

As reported in the previous newsletter, the Government response to the Legislative Council’s Select Committee on off-protocol prescribing of chemotherapy in New South Wales was provided to the committee on 20 November 2017.

The Executive Committee will monitor any developments that may occur in relation to the events covered by the inquiry and in relation to off-protocol chemo dosing throughout the year. In late 2018, at the twelve-month point from the provision of the Government response, an update will be requested from the Minister for Health on the implementation of the report’s recommendations.

Murray McLachlan

COSA Tele Trials Consortium

“Access to clinical trials for people diagnosed with cancer is a core component of providing optimal cancer care through specialist cancer centres, hospitals and other treatment facilities. Patients living outside of major metropolitan centres face many barriers in accessing clinical trials.

Barriers to participation include the limited availability of trial sites closer to home and the increased cost and inconvenience of travel to major centres where the trials are taking place”.

(extract from MTPconnect Website)

The Australasian Tele-Trial Model was developed by the Clinical Oncology Society of Australia (COSA) and uses tele-health to facilitate clinical trial activity. COSA is now leading a project to pilot the implementation of this Model in Australia. Cancer Voices and Rare Cancers Australia are two consumer groups that are part of this consortium.

Elisabeth Kochman

Survivorship - Patient Reported Outcomes - Focus Groups 2018

Imogen Ramsey (from SA) is undertaking a PhD to develop a core data set of ‘survivorship’ issues for population level monitoring of cancer outcomes that are important to cancer survivors.

Focus groups were recently conducted in Sydney and Adelaide by Imogen on Survivorship – Patient Reported Outcomes, which were well attended.

Cancer survivors were given the opportunity of having a voice in sharing our experiences and what could have been better. Many insights were shared in a short space of time into a range of physical, psychosocial and practical challenges faced by people with cancer.

Imogen commented on the combined feedback across all groups, that although some themes were common across our experiences, groups raised different perspectives and opinions which made for a rich and insightful discussion.

The three types of ‘Patient Reported Outcomes’ that Imogen is studying are where reported outcomes are used for individual care, where feedback and outcomes are used to inform local services and where feedback is used for monitoring at the state and national level.

The work will align with a similar Netherlands Program led by Prof Lonneck van der Pols, who was a keynote

speaker at the recent Survivorship Conference in Melbourne.

Imogen is spending 6 months in the Netherlands to learn about the implementation of the PROFILES registry (<https://www.profilesregistry.nl/>), the only system in the world for tracking quality of life in cancer survivors post-treatment on a population level.

The issues raised in the focus groups will be put forward for consideration in the cancer survivorship core outcome set. The next step will be to refine and prioritise the most important outcomes from the perspective of survivors, health professionals and clinicians. Those who participated in the in the focus groups will have the opportunity to participate further in this process by completing an online questionnaire.

We wish Imogen all the very best. This study is greatly appreciated in the progression of some of the unmet needs of cancer survivors.

Note: Thanks to HCNSW for providing a venue for the Sydney focus groups.

Shirley Baxter

Thanks Christine

CVN thanks Christine Nolan for her contribution as CEO of **Breast Cancer Network Australia (BCNA)** for the last three years.

Christine has advised she will be leaving BCNA in mid-April to spend more time with her daughter, son-in-law and two-year-old granddaughter. Her daughter was diagnosed with metastatic bowel cancer soon after giving birth. Christine says the time has come to be available to spend more time supporting her when required.

We would like to say Thank You, Christine, for your initiatives over the three years; you have led BCNA, including the Metastatic Cancer Alliance and advocacy achievements of superannuation funds for terminally ill Australians and the PBS listing of Kadcylla and Perjeta.

BCNA is in its 20th year and forthcoming BCNA events include:

- State of the Nation Launch June, Canberra
- Plan B survivorship conference, 11 August, Melbourne
- [Field of Women](#), 12 August, Melbourne

Susan Pitt



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 2017 to the end of February 2018, CVN has matched 43 consumers to 30 projects. However, these figures don't reflect the true impact of the CIR program. 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.

The Executive Committee are members of 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.

Growth and consistency of the program is reflected in the following statistics from the same period of previous years:

- December 2014 to the end of February 2015
CVN matched 21 consumers to 20 projects;
- December 2015 to the end of February 2016
CVN matched 30 consumers to 22 projects;
- December 2016 to the end of February 2017
CVN matched 28 consumers to 21 projects.

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 survivorship care plans for childhood cancer survivors, unwanted variations in clinical care, a review of outpatient clinic chart packs and information booklets, and tailoring the next generation of cancer therapy to older patients. There is a broad range of cancers being investigated, including brain cancers, head and neck, and osteosarcomas. There have been several requests for consumers from interstate universities and institutions. For these projects, the consumer is able to engage with the research team via teleconference or Skype.

The *Consumers in Research training program* has been changed to a new format. Trainees undertake the theory section of the training course online. The link to

the online section of consumer training is available on the Cancer Council Australia website. It is a series of four short online modules designed to inform and prepare consumers to be involved in health and medical research. Once the trainees complete the online modules, they can register with Cancer Council NSW to complete a face-to-face half day workshop. This workshop is usually held in September, at the CCNSW Woolloomooloo office. Here the consumers meet researchers, workshop scenarios and are involved in discussions which prepare them for their contribution to cancer research.

Cancer Voices NSW acknowledges the time and effort our consumers give to cancer research. Thank you for your work on committees and projects to ensure quality cancer research which benefits all of us on our cancer journey.

Lee Hunt

The Australian Cancer Research Foundation (ACRF) Image X Institute

Late last year saw the launch of a new institute at Sydney University. The event was hosted by journalist and head and neck cancer survivor, Julie McCrossin. The ACRF Image X Institute's work aims to revolutionise medical imaging, pioneer functionally targeted radiotherapy and enable global access to cancer radiotherapy. It is a world-leading centre for basic and translational medical innovation.

One area of research undertaken at the Institute is the LARK Clinical Trial. This trial will take KIM technology and apply it to liver tumours. KIM guides and monitors radiotherapy treatment to tumours in real-time, improving accuracy of the radiation beam, therefore reducing radiation dosage and side effects. The tumour and healthy tissue almost always move during treatment. This motion, if unaccounted for, results in the tumour receiving a lower dose and healthy tissue receiving higher doses than desired. A large part of the research program is dedicated to aligning the radiation beam with the tumour as it moves during radiation treatment.

KIM is a technology that is compatible with standard radiotherapy systems currently in use all over the world, with the potential to improve outcomes for cancer patients globally. The LARK Trial will strengthen the case for the use of KIM worldwide, and lead to trials for lung, kidney and pancreas tumours.

There is a massive global demand for affordable radiotherapy machines. Another area of research being undertaken at the institute is Nano-X radiotherapy. It is a new class of radiotherapy system that will deliver significant cost reductions, by introducing clinical precision with a machine that has a significantly smaller footprint, reduced shielding requirements and lower staff-to-patient ratios. The research team are developing this machine with a fixed treatment and imaging beams, and a custom-made patient rotation system. The system is built with real-time guidance and adaption. Complex processing tasks have been moved from hardware to software, enabling radical changes to the machine's design.

These innovations will ensure better treatment outcomes and increased safety and reliability for cancer patients.

Lee Hunt

Brain Cancer Biobanking

Brain Cancer Biobanking Australia (BCBA) is a virtual biobank hub established to provide researchers easy access to the amount, quality and type of tissue and associated data they need to accelerate both paediatric and adult translational brain cancer research. BCBA is committed to supporting research performed by clinicians and scientists working in both the paediatric and adult brain cancer fields.

The consortium has been established under the umbrella of the Cooperative Trials Group for Neuro-Oncology (COGNO) with the goal of accelerating brain cancer research and the translation of that research into improved outcomes in patient care.

Read more here <http://www.bcba.org.au/>



Consumer Reps Program

Cancer Voices continues to provide nominees on request by stakeholders, via our website **Request a Consumer Representative** form. We make it clear that those nominees are informed and are there to represent the broad view of people affected by cancer – not of the organisation itself, or of an individual alone. These requests are usually made by cancer professional organisations, government agencies and health service planners.

Training: Please check the **Noticeboard P2** for information about the next Consumer Advocacy Training (CAT) course to be held by the Cancer Council NSW (CCNSW) in **May 2018**. Cancer Voices always welcomes new members who have completed a CAT course and looks forward to introducing them to our activities, advocacy and research programs, as well as hearing their ideas about issues for people affected by cancer. Our thanks to Carolyn Grenville and her team at CCNSW for providing this training.

The Voices being heard

Meetings

- Cancer Council NSW Central Coast, Erina, 11 January
- Health Consumers NSW, 24 January
- Cancer Council Australia Less Common Cancer Resource Advisory Committee, 30 January (teleconference)
- Garvan Institute (teleconference), 1 February
- Lymphoedema Action Alliance, 6 February
- Radiation Therapy Advisory Group (RTAG), 13 February
- Targeting Cancer Planning Meeting, 16 February
- NSWOG - Neuro Oncology, quarterly meeting, 16 February (teleconference)
- CVN AGM, 16 February
- RANZCR Interventional Radiation Committee (teleconference), 20 February 2017
- Insurance Project, 23 February
- Cancer Council Australia Less Common Cancer Resource Advisory Committee, 26 February (teleconference)
- RANZCR FRO Council Planning Meeting, 1 March

- RANZCR FRO Council, 2 March
- COSA Teletrials Consortium, 6 March
- UTS, various / ongoing

Conferences / Forums/ Events

- Survivorship Focus Groups (SA PhD project), 16 January
- Peter Mac Survivorship Conference Melbourne, 8-9 February
- CVN Workshop, 16 February
- Australasian Oncology Summit (RT) Brisbane, 23 February
- CCNSW Onboard for a Cause, 1 March

Surveys

- Consumers Health Forum Australia "Out of pocket pain survey"
- HSC project on the design of Cancer Centres, February

Cancer Council NSW Update

Announcing our new Financial Navigator service

Cancer Council NSW Financial Assistance Services has introduced a new initiative, a **Financial Navigator**, to provide people affected by cancer with even more effective and seamless financial information and support. A cancer diagnosis can have a significant impact on an individual's financial circumstances and Cancer Council NSW's Financial Assistance Service supports people affected by cancer to access much needed financial assistance. To complement this service, the Financial Assistance team introduced the Financial Navigator role in October 2017 to provide financial information and refer people affected by cancer to appropriate financial support services.

This initiative means that people who call Cancer Council NSW's Information and Support line with

financial issues can speak directly with a Financial Navigator who is able to answer financial queries or assist eligible clients with an emergency financial grant in the form of bill payments for a range of household expenses, emergency food and fuel vouchers for transport to treatment. The Navigator is also able to refer eligible clients to one of Cancer Council NSW's financial counsellors who provide advice in relation to debt management and dealing with creditors, or to the Cancer Council Pro Bono Program which can connect clients with external financial planners who provide free advice. Since October 2017, the Financial Navigator has received 980 calls from people seeking financial information and support.

Speak to your social worker or call 13 11 20 to access Cancer Council NSW's Financial Navigator.



Cancer Institute NSW Update

Outpatient Cancer Clinics Survey – understanding the patient experience

The Bureau of Health Information (BHI) manages the NSW Patient Survey program on behalf of the Ministry of Health. As part of the program in 2015 BHI worked with the Cancer Institute NSW to develop the Outpatient Cancer Clinics Survey (COPS).

The survey is tailored to elicit views, observations and experiences of patients who had recently attended a cancer outpatient clinic. Outpatient clinics are defined as oncology, chemotherapy and radiotherapy services. Currently, all public cancer outpatient centres and some private cancer centres participate in the survey.

Results of the survey provide a valuable resource to providers of cancer services in NSW - to benchmark performance in relation to the NSW average, with other cancer centres and to identify system performance initiatives.

The Bureau of Health Information, in collaboration with the Cancer Institute NSW, will be running the survey for the third time in 2018, for patients who visited an outpatient cancer clinic in November 2017.

The questionnaires and results of the surveys for both 2015 and 2016 can be found on the BHI website:

www.bhi.nsw.gov.au/nsw_patient_survey_program/outpatient_cancer_clinics_survey

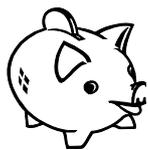
Development of resources to promote screening among Aboriginal people

The Cancer Institute NSW has recently developed and launched some new Aboriginal screening resources including two postcards to promote bowel screening at Aboriginal men's and women's groups and events. Additionally, a pull-up banner and resource presentation folder have been designed to promote the various cancer screening and prevention services among Aboriginal communities.

National Indigenous Bowel Screening Pilot

As a supporting agency, the Cancer Institute NSW continues to work with the Australian Government Department of Health and Menzies School of Health Research to support planning for the National Indigenous Bowel Screening Pilot. The Cancer Institute NSW is currently undertaking activities aimed at improving engagement with and promoting participation by local Aboriginal Community Controlled Health Services and Aboriginal Medical Services in NSW.

Save the Date: Thursday 13 September 2018



The Cancer Institute NSW is shaping up for its annual ***Innovations in Cancer Treatment and Care Conference*** to be held at the Sofitel Sydney Wentworth on ***Thursday 13 September 2018***.

This year's keynote address will be provided by Dr Craig Earle, Director for the Health Services Research Program for Cancer Care Ontario and the Ontario Institute for Cancer Research. Dr Earle's research program focuses on using administrative data to evaluate the accessibility, quality, costs and outcomes of care delivered to cancer patients and survivors.

The Innovations Conference is a free event that provides an opportunity to learn collaborate and

share the latest innovations in quality cancer treatment and care.

Smoking Cessation Framework released

The Cancer Institute NSW has released the Smoking Cessation Framework for NSW Health Services on behalf of the NSW Smoking Cessation Collaboration. The Framework is a resource to support local health districts (LHDs) to implement smoking cessation interventions for patients and clients who smoke.

The Institute is working in partnership with LHDs to support the implementation of the Framework. Framework Planning Workshops are offered to all LHDs as an opportunity to bring together key stakeholders to develop an implementation plan.

For more information, visit

www.cancerinstitute.org.au/smoking-cessation



Special Report: Consumers reporting on conferences

➤ **The 2nd Victorian Cancer Survivorship Conference**

The conference **'The Survivorship Equation. 'Evidence + Best Practice = Better Outcomes'** was held on 8-9 February 2018 in Melbourne with representation from Cancer Voices NSW and SA.

The Cancer Survivorship Conference was presented by the Victorian Comprehensive Cancer Centre and the Peter MacCallum Cancer Centre, with Associate Professor Michael Jefford as Conference Convenor.

The Conference was well attended and an outstanding success with international speakers from the USA, Canada and The Netherlands with each country presenting on their experience in providing comprehensive cancer care and Survivorship Care Plans.

The conference also included of an impressive number of abstract "Rapid Fire" sessions, themed into eight relevant areas, culminating in Building Models of Care. Cancer Voices SA had an impressive Poster titled 'Survivors in the survivorship equation: survivor evidence + survivor views of best practice = better outcomes', which attracted a great deal of interest. *For further details and a link to the poster see the Poster Overview which follows this review.*

Rochelle Serry, 10 years all clear from Hodgkins Lymphoma, gave a compelling consumer presentation, *'Things that matter'*, on the challenges of navigating the pathway from diagnosis through treatment,

communication challenges and beyond when leaving primary medical care.

Cancer survivors are increasing in number. Relative five year survival rates for all cancers have increased significantly over the last 20 years with over 1 million Australians living with or beyond cancer. This number will increase greatly with our ageing population and continuing improvements in diagnosis and treatment.

The conference provided a great deal of inspiration in the area of transforming Survivorship Care and the experience of introducing personalised Care Plans in other countries, as well as those available to each survivor receiving treatment at The Peter MacCallum Cancer Centre back home in Victoria.

Survivorship continues to be a key focus area for Cancer Voices NSW in 2018.

Shirley Baxter

➤ **Survivorship Poster Overview:**

Survivors in the survivorship equation: survivor evidence + survivor views of best practice = better outcomes.

"Can cancer survivors help teach doctors, to enhance their communication skills and understanding of our experience?" That was a question posed by Julie Marker at a 'Festival of Ideas' book review session, in October 2011. The oncologist presenter didn't have an answer, but a medical educator in the audience came over to speak to Julie after the session. This led to an ongoing collaboration, co-designing a series of

survivor-led small group tutorials, 11-15 sessions per year with 3rd year medical students at Adelaide University. The overwhelmingly positive feedback from students and their 'reflective piece' assignments indicate they are deeply affected by the presenter's stories and a 'transformative learning process' takes place within the program. Since 2012, Julie has coordinated and supported a growing group of 'survivors as teachers' to present interactive tutorials with 8-12 medical students per session. Variations on this model have since been developed for nursing, allied and other health students at the University of South Australia and Flinders University. Since 2012, the 'Survivors as Teachers' program has involved more than 1350 students, 100 interactive tutorial sessions, 50 cancer survivors covering 200 session attendances to present a diversity of cancer types, personal circumstances and backgrounds. **YES - survivors CAN be very effective teachers.**

This poster can be viewed here:

<http://www.cancervoicessa.org.au/assets/documents/posters/cvsa-2018poster.pdf>

**Chris Christensen (Chair),
Julie Marker (Deputy Chair), Cancer Voices SA**

➤ **The Australasian Oncology Summit - Brisbane - 23 February**

The summit provided insights into new oncology technologies. In particular, I participated in the interactive sessions that progressively took participants through the 360 Oncology care management software package, available for cancer healthcare providers. This package is designed to provide cancer care that improves patient outcomes in an environment that is more integrated, collaborative and patient-centred.

The software program connects referring doctors and cancer specialists; integrates evidence, outcomes data, guidelines and care pathways; coordinates multiple treatment sites; and engages all stakeholders involved in cancer care, including the patient and their care support team. It uses an overarching Cloud System that can be accessed from any computer or mobile device, allowing patient access through the patient portal. It is a secure site needing pin access which ensures privacy.

The program integrates software in all aspects of the patient's journey: including electronic referral management and multi-disciplinary team meetings, treatment prescription and planning, treatment delivery and patient follow-up and survivorship.

This oncology software system commences with the patient's referring doctor. When the results of the

patient's diagnostic imaging are received, the doctor is able to log into the system and send the referral directly to the oncology clinic, along with the diagnostic data. This information is then available to all members of the multidisciplinary team that will be involved in the patient's treatment. The cancer team can directly request from the referring doctor all relevant information, such as allergies, scans and lab results and previous medical history.

Following this, the patient becomes registered with an oncology doctor and an appointment is made for the initial consultation. The patient's doctor is sent an appointment schedule. The doctor can access all data and can directly email any part of the oncology team requesting information. Educational material can be sent to the patient via the patient portal. Printed information can be generated for patients who choose not to log into the portal. Other areas of the software package include: calendar treatment schedules, patient health information such as toxicities and other health issues, surveys on how the patient is coping throughout the treatment and a comprehensive follow-up care plan.

There are also tools in the program that help the multidisciplinary team decide on the best treatment path, such as data on side effects of treatment options. All diagnostic images can be viewed by each member.

The program improves patient engagement throughout their cancer journey. It improves the patient's compliance with scheduling and reminders, it arms patients with test results and educational information and it collects patient-reported outcomes through surveys and inquiries about symptoms experienced. Documents can be created and sent to the patient, including care plan summaries that outline what has happened, follow-up care plans and any information that is relevant to the patient. The patient is able to send messages to their care team at all stages throughout the oncology continuum. It also includes a journal section that can be tracked by the care coordinator post treatment, allowing continuing cancer care team collaboration.

Lee Hunt

➤ **Improving Oncofertility Care for Cancer Patients Research Project**

Most populations across the globe consider children to be a priceless commodity. No other age group is considered more precious and this is echoed in the importance people place on the ability to have children. Oncofertility care includes fertility preservation (FP), management of sexual dysfunction, management of

hormonal deficiency, complex contraception and fertility related psychosocial support. These are increasingly important medical and quality of life issues for cancer survivors and one of the top five unmet needs for cancer patients. Therefore, wherever possible, oncofertility care should be an integral part of cancer care from diagnosis through survivorship.

What is the research and whose support is required?

The Global Framework For Oncofertility Care (G-FORCE) is seeking the support of cancer patients, survivors, parents and care givers to participate in a survey about oncofertility (cancer + reproduction) care so that clinicians around the world can provide improved fertility preservation care, resources and support. The survey, which seeks information on the delivery of fertility preservation care experienced, is extremely important, as it will assist health care professionals to improve oncofertility models of care, resources and support for cancer patients, survivors, families and care givers. This may include improving referral pathways for cancer patients from cancer doctor to fertility specialist to allow a fertility consultation with a specialist to discuss the importance of fertility preservation options and strategies (egg freezing, embryo freezing, ovarian or testicular tissue freezing, sperm banking) prior to starting cancer treatment.

'I was fortunate that when Dr. Anazodo talked about the complications of my cancer treatment and she let me know about fertility preservation. Rather than trying to give me all the information in one day we had a separate meeting and I was given the opportunity to

talk alone. I choose to have IVF before my treatment started and the cancer and fertility team worked together so that all my pre-treatment tests and fertility procedures happened together. I felt supported making decisions and I was relieved that I was given honest accurate information that I could understand'.

Zoe, 19 year old Ewing's Sarcoma patient

Who is doing the research?

The study is being led by Dr. Antoinette Anazodo, Paediatric and Adolescent Oncologist, Kids Cancer Centre, Sydney Children's Hospital Antoinette.Anazodo@health.nsw.gov.au with an international group of cancer and fertility clinicians across a number of disciplines (nursing, psychology, social work, medicine and surgical specialties) in Australia, America, Brazil, Canada, India, Japan, New Zealand, Portugal and the United Kingdom.

What involvement is expected?

Involvement requires an anonymous online survey which takes approximately 30 minutes to fully complete (it does not need to be completed in one sitting) and will involve indicating your level of agreement with each statement about the delivery of fertility preservation care experienced to date. You will also be given an opportunity to provide comments at the end of the survey. Please click on the link below to access the survey:

<http://www.futurefertility.com.au/research-tab/oncofertility-competency-framework/>

The survey is available in the following languages: English, Spanish, French, Portuguese for European and South Americans, Japanese and Hindi.

CanDo helps turn empathy into action, making it easier for people with cancer to get the help

CanDo is a new, free mobile app developed by advertising executive and breast cancer survivor Rachael Lonergan in collaboration with the Garvan Institute of Medical Research.

The Australian-developed app helps people with serious illnesses get assistance with everyday tasks, while removing the awkwardness of asking for help.

After completing a year of treatment, Rachael realised she should have accepted more help but that broaching the conversation with family and friends can be difficult. She came up with the idea for the CanDo app, a team and task management tool. *"The app helps to*



eliminate social isolation and allows people to focus on their treatment, reducing anxiety around getting the 'little things' done." Rachael said.

Whether you're dealing with an illness yourself or know someone who is, CanDo can help share the load of completing everyday tasks. The CanDo app is designed to help people with an illness, on their terms.

The CanDo app is free to download and to use and is available now in both the [Apple App Store](#) and [Google Play](#).

For more information, go to www.candoapp.com.au
For video link...<https://youtu.be/nijl7elFgfg>



Cancer Voices NSW Annual Report 2017

It is with pleasure that I present the Cancer Voices NSW 2017 Annual Report as our seventeenth year ends which highlights the activities of 2017. - a year of transition, consolidation and getting on with business.

We began the year with the reality of the passing of Sally Crossing AM. Saturday 4 February (also International Cancer Day) saw the entire EC join some 300 guests at the Celebration of the Life of Sally Crossing AM at her alma mater, the University of Sydney. We heard tributes by the Chancellor, family members and colleagues. Tributes have continued throughout the year in many forms. Recognition has come from professional organisations, agencies and individuals who had worked with and known Sally over many years.

In February, we held the Consumer Involvement in Research (CIR) Refresher session (kindly hosted by CCNSW). This has helped equip our CIR reps with more skills and understanding of the research process. The Refresher resulted from the findings of our 2016 survey of consumers and researchers which formed the basis of our publication *Cancer Voices Consumers in Research (CIR) Evaluation Study* (released and distributed in August 2016). See www.cancervoices.org.au

We finished 2017 with receipt of the trademark registration for our *Consumers Included* logo. With it now registered, the future potential for this initiative is enormous. See <http://consumersincluded.wordpress.com/>. *Consumers Included (Ci)* – a logo “seal of approval”, shows that the organisation is committed to engagement with consumers in a meaningful way. Ci was launched in April 2016 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.

Cancer Voices NSW (CVN) continued to be strongly engaged in state and national level activities, the latter

through Cancer Voices Australia (CVA) and the Australian Cancer Consumer Network (ACCN) facilitated by CVA.

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 such as funding cuts for radiation therapy equipment. The Executive Committee (EC) identified a range of priorities for 2017 with focus on three key issues: *Palliative Care; Lymphoedema and Cancer Nurse Coordinators*. With the next state election in 2019, we will be busy promoting our position with the major parties and politicians.

The “voice” was heard on many issues during 2017 including:

- 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 the cancer workforce, especially cancer nurse coordinators
- Support for consumers attending cancer conferences
- Consumer engagement in research
- Affordable access to highest quality care
- Access to new drugs
- Insurance issues for people affected by cancer
- Medicinal Cannabis
- Safety & Quality in Cancer Care. Best practice standards following “chemo dosing incidents” in NSW & SA
- Federal funding cuts to radiation equipment
- Access to clinical trials including via the COSA Teletrials Consortium
- Metastatic disease including via Australian Metastatic Cancer Alliance (AMCA)
- Provision of prescription medicine information inserts or CMI with all medication
- National Health Genomic Policy Framework
- Low survival and less common cancers
- Availability and accessibility of diagnostic equipment around Australia

- Ministerial Roundtables: Consumer centred primary care; Radiation Oncology equipment funding

Note: More details can be found in our 2017 newsletters Nos 66-69 incl at www.cancervoices.org.au

Cancer Voices welcomed the release of the revised Clinical Oncological Society of Australia (COSA) *Survivorship Model* in June and the Cancer Australia’s *Principles of Survivorship* in August. CV had advocated for this important work and welcomed the opportunity to work closely with both organisations on their respective projects. We are also delighted to be a member of the COSA Teletrials Consortium which aims to improve access to clinical trials for those in regional and rural areas.

Award for Excellence in Cancer Consumer Advocacy 2017: Cancer Voices recognises those advocates and consumer representatives who demonstrate excellence in their activities. The sixth annual award was posthumously awarded to Sally Crossing AM at the Cancer Council NSW’ (CCNSW) annual Research Awards on 1 March.

Working with Stakeholders: CVN nominees and the group itself continue to work with the wide range of cancer world stakeholders forging relationships at both state and national levels.

Consumer Representation and Training: *Consumer Advocacy Training (CAT)* courses were held with CCNSW in February, June and October. Graduates are invited to join Cancer Voices. A *Consumer Involvement in Research (CIR)* training course was held in September with CCNSW using a new format comprising four online modules and a half day face to face workshop. This provided 11 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 continues to increase each year and has been coming from further

afield. Lee Hunt continues to manage this important program.

The Written Word: Four 16 page newsletters were published during 2017 and mailed to members and stakeholders. They are also available on our website for wider access. 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. The December newsletter was our 69th issue. Cancer Voices is also responsible for the production of Cancer Voices Australia (CVA) *News Updates – during 2017* – with four of these during 2017. Major submissions, reports, reviews and posters can also be found on the CVN website, whilst those related to national issues are accessible on the CVA website.

Speaking Out: During 2017 members continued to attend workshops, seminars, events and conferences, contributing the consumer view, taking the opportunity to network and keeping up to date in the “cancer world”. CVN representatives continued to give invited addresses and presentations, to appear before related government inquiries, meet with government ministers and to contribute to media discussion.

Organisational: We continue to see a steady increase in our membership. New members are welcome to join our advocacy activities.

We remain an entirely 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 growing database and Kathryn Leaney who formats our newsletter.

Vale Kathy Smith: (Former Executive Committee Member) Cancer Voices was deeply saddened by the death of another staunch advocate and “friend”, Kathy Smith, on 31 May. Kathy was a former Deputy Chair and Chair of CVN and worked at local, state and national levels. She became the State MP for the Central Coast in 2015. Kathy was well known for her campaigning, initially for public radiotherapy services for the Central Coast. Her efforts resulted in a \$38m Cancer Centre for Gosford Hospital which opened in 2013.

Cancer Voices SA (CVSA): CVN congratulated CVSA on reaching its ten year anniversary. The two organisations have worked closely together on several issues during 2017 and we look to build on this rapport going forward.

The Executive Committee (EC): The EC held a special meeting in January and then met every two months in the CBD. Our first meeting was at the offices of Enstargroup, courtesy of Sandra O’Sullivan, our Treasurer, and thereafter at Health Consumers NSW (HCNSW). We have also used teleconferencing and met out of session as necessary.

Members for 2017 were Elisabeth Kochman (Acting Chair), Murray McLachlan (Hon Sec), Sandra O’Sullivan (Treasurer), Bev Noble, David Campbell, Peter Brown, Roberta Higginson, Lee Hunt, Jan Mumford, Susan Pitt, Shirley Baxter, Sarah Lukeman and Elaine George. Their work in a number of special interest areas has made a big

difference to our ability to achieve desired outcomes.

Financial: The Treasurer’s Report for 2017 is presented separately. As a voluntary organisation we are grateful for all donations received, no matter the amount, as it all helps. Cancer Voices is especially grateful to be the beneficiary of a generous donation in honour of Sally Crossing AM by the UBS AG giving program. 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 new home for our meetings during 2017, Geoff Vass and Melissa Cadzow of Cadzow TECH Pty Ltd who ably assist with IT and website needs and issues. A BIG thank you to all.

To members of the Executive Committee and to our nominees who work in positions as consumer representatives in the decision-making “cancer world”, thank you for your wonderful support, 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,
Acting Chair 2017**





Trademark registration for *Consumers Included* “seal of approval”: We finished 2017 with receipt of the trademark registration for our *Consumers Included* logo. With it now registered, the future potential for this initiative is enormous. See <http://consumersincluded.wordpress.com/> *Consumers Included (Ci)* – a logo “seal of approval”, shows that the organisation is committed to engagement with consumers in a meaningful way. Ci was launched in April 2016 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.

The added value and benefit of including informed consumers in cancer conferences, forums and other events, for the organiser, the attendees, representative consumers and their networks, has been demonstrated and is now well accepted. To promote and encourage this practice, a “seal of approval” logo was developed and is now available for use. This Cancer Voices initiative continues to attract interest.

The approved organisations are listed on the CI website and details can be found at <http://www.cancervoicesaustralia.org/consumers-included/> and <http://consumersincluded.wordpress.com/>.

Update: Funding Reductions to the Radiation Oncology Health Program Grants

Radiation therapy is involved in around 40% of all cancer cures, but is still underutilised in Australia. While 1 in 2 patients would benefit from radiation therapy at some point in their cancer journey, only 1 in 3 actually receive it.

Though radiation therapy is very cost effective, radiation therapy equipment has the highest capital cost of any equipment used in health service delivery. Through the Radiation Oncology Health Program Grants (ROHPG) Scheme, the Commonwealth Government has been contributing to the cost of all equipment used in the delivery of radiation therapy, which has allowed radiation therapy equipment to be upgraded or replaced as required, typically every 10 years. At the end of 2016, the Commonwealth Government announced a significant reduction in the ROHPG Scheme, to take effect from 1 July 2017.

All patients who need radiation therapy will be affected, including patients being treated with curative intent or those who might need it to relieve symptoms caused by cancer. There will be reduced ability for patients to access life prolonging radiation therapy, especially specialised techniques such as brachytherapy, intensity modulated radiation therapy (IMRT) and radio surgery. This will particularly affect rural and regional patients whose access is already limited. Patients will have increased out-of-pocket costs and may need to travel further to access the most appropriate treatment,

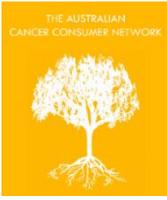
removing them from their families and supports for extended periods of time.

A new alliance named the Radiation Therapy Advisory Group (RTAG) has been formed to raise the profile of radiation therapy, particularly with policy decision makers, and ensure it is adequately resourced in future health planning right around the country. Its primary focus is predominantly on the fundamental matter of radiation therapy's underutilisation and some of the ongoing problems for cancer patients resulting from changes to the ROHPG scheme. The group comprises of a diverse spread of radiation therapy stakeholders, has public campaigning clout and is chaired by Dr Peter O'Brien. Dr O'Brien is an experienced radiation oncologist, practicing in Newcastle.

Cancer Voices Australia has joined the alliance. Presently we are seeking other cancer consumer organisations that would like to support the work of the alliance. As a result of consistent consumer advocacy, with petitions to both the Federal and State Governments, a cancer centre is being built at Dubbo Hospital. Previously the closest radiation therapy machines were at Orange Hospital, making treatment unavailable for many cancer patients in the North Western region of NSW.

If your regional and rural centre has no or poor access to radiation therapy, please contact us by email at - info@cancervoices.org.au

Lee Hunt



Australian Cancer Consumer Network (ACCN)

An update and revitalization of this network is currently underway with details currently being checked.

Once completed the **ACCN Who's Who Directory** will be updated on the website.

Thank you to our colleague Dan Kent (QLD) for his assistance in this task.

Background: For those of you not familiar with this network, the Australian Cancer Consumer Network (ACCN) was launched at Parliament House, Canberra in November 2014. The ACCN brought together 30 groups and organisations to provide a bigger voice as well as to share information, experiences, action techniques and issues. It is facilitated by Cancer Voices Australia (CVA). CVA then Convenor, the late Sally

Crossing AM, said of the network at the launch, *"bringing us all together like this for the first time is exciting and empowering. It shows that our national representatives are truly keen to be connected to the needs and ideas of people affected by cancer. The ACCN can speak to decision-makers with one voice when necessary, especially in a time of increasing pressures on our health system, greater need than ever before to access treatments for people with cancer or for helping smaller, less known cancers to be heard"*.

The Parliamentarians invited CVA to co-host and organise this first of its kind event through Parliamentary Friends - Parliamentarians Supporting Cancer Causes, so that MPs and Senators could meet people affected by cancer. All present received a copy of the **Who's Who in the ACCN** directory – a valuable resource making it easy for all to connect with the various cancer consumer groups.

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 and labels, Murray McLachlan for proof reading and Elisabeth Kochman as compiler & Editor & all our contributors.

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.

Cancer Voices NSW also greatly appreciates the assistance given by Cancer Council NSW (Peta Dunn & the packing team), for printing & posting Cancer Voices Newsletters.



REMEMBER On- Line Access

All our newsletters are available via our website. This may assist you when accessing links and web addresses that are included with many of our articles.

Saving Life 2019 – Collecting stories



Cancer Council NSW has recently committed to campaigning for **more support for people with lymphoedema**, in the lead up to the NSW state election in March 2019. We will be asking the NSW Minister for Health to provide funding for a lymphoedema service in each Local Health District, according to population need.

CCNSW will of course be working alongside the Lymphoedema Action Alliance throughout the campaign.

One of the **key components of the Saving Life 2019 campaign will be the use of story** to support our campaign requests and influence the views of candidates, political parties and the next NSW Government. We will be using these stories across social media and local media; local candidate and community forums; when meeting with local MPs and other decision makers and in written materials.

We would love to hear from people who have an experience, either positive or negative, of accessing public treatment for their lymphoedema. Did you have trouble getting the treatment from the public hospital in your local area? Did you get treatment and did it make a positive difference to your health and wellbeing? Was sufficient information provided at time of diagnosis?

The experience could be from someone who has lymphoedema or a loved one or a therapist. Your experience needs to be **reasonably recent** (say the past few years) and needs to be about treatment **in NSW** (not in other States). We are looking for people who are prepared to share their story publically (with permission of course.)

The template (overleaf) can be used to provide details of that experience.

Please email the completed template to Carolyn Grenville at

carolyng@nswcc.org.au

or call 9334 1855 for more information.

Saving Life 2019 – Collecting stories

MY STORY- SUPPORT FOR PEOPLE WITH LYMPHOEDEMA
Name:
Suburb:
Phone number (so we can contact you to do a follow up interview if needed) ()
<i>When, where, and what were the circumstances of your being diagnosed with lymphoedema? Was your lymphoedema a result of treatment for cancer or some other condition?</i>
<i>Once diagnosed, how easy or difficult was it to access treatment for lymphoedema?</i>
<i>Can you give us further details of your experience? What was the impact on you and your loved ones? Where did you go for information? Was the information provided useful?</i>

Please email to Carolyn Grenville carolyng@nswcc.org.au or call 9334 1855 for more information.