

MESSAGE TO MEMBERS

As we head for our fifteenth birthday in October (Cancer Voices was born in October 2000), I notice that we are up to the sixtieth edition of the Cancer Voices NSW Newsletter. That could almost make a book about those 15 years, and may be it will one day! All our newsletters are on the website and held in Legal Deposits of the State Library NSW and the National Library – so the record is safe.

We recorded our first ten years in the booklet *Cancer Voices NSW – A Decade of Success*. This is accessible via our website, but if you'd like a hard copy, we still have supplies.

Interesting to note that Cancer Voices is older than Cancer Australia and the Cancer Institute NSW – both agencies for whose establishment we had advocated strongly, and had much input during their development and implementation.

Issues survey 2015

Cancer Voices has created a survey using the tool, Survey Monkey, to assess the current principal issues for people affected by cancer. This is important for the direction of our advocacy work and as the basis for our approach to our political representatives in the lead up to the next federal election.

You will find a survey insert with this Newsletter. Please complete and mail or scan/email back to info@cancervoices.org.au so we know what YOU think. It will also go to the 30 consumer related groups in the Australian Cancer Consumer Network, which is facilitated by Cancer Voices Australia. We will of course publish the results in the next Newsletter.

Informed consent: A big issue which has resurfaced is that of getting sufficient information to make good decisions about cancer treatment, its location and any costs likely to be incurred - written so it can be considered and discussed with others. Cancer Voices has developed a Position Statement about this which is now on the website.

Cancer Voices, through Cancer Voices Australia, has continued to support the Regulator of Medical Cannabis Bill which we hope will soon be considered by the Senate, following the Senate Inquiry's very positive recommendations.

This year sees the tenth anniversary of our **Consumer Involvement in Research Program**. An outline of its development and achievements has been accepted for publication in the November issue of the journal, *Cancer Forum*, and will be available in this Newsletter in December. It's our policy to record the good things we do, when we can!

This has been a great year for working with other organisations which have similar interests and who value our support, for example, the Lymphoedema Action Alliance. Not to mention being a founding group within the Australian Cancer Consumer Network.

We always appreciate your interest and support towards improving things for people affected by cancer in NSW – and indeed beyond. Here's to the next fifteen years, IF our advocacy is still needed (wouldn't it be great if it were not!).

Very best wishes
Sally Crossing AM, Chair & Editor



Happy 15th Birthday, Cancer Voices



CVN Notice Board



Consumer Advocacy Training : 13-14 November 2015

Opportunity knocks!

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://canact.com.au/advocacy-training/>

For further information: Policy & Advocacy Unit, Cancer Council NSW

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



Consumer Involvement in Research (CIR) – Annual Training Day 20 November.

All those keen to work with cancer researchers as consumer advisors nominated by Cancer Voices should contact John Williams at johnw@ccnsw.org.au and ask for an Expression of Interest form



Future medicinal cannabis trial - anonymous survey invitation

- Are you living with advanced cancer?
- Do you suffer from loss of appetite, taste problems or weight loss?
- Might you consider taking part in a clinical trial of cannabis products in the future?

If the answer is 'yes' to all three questions, we invite you to complete an anonymous survey to tell us more

about your preferences. The survey will take about 5 minutes and can be found at <https://www.surveymonkey.com/s/cannabistrial>

This study is being conducted by Palliative Care Clinical Studies Collaborative (PaCCSC) in association with Improving Palliative Care through Clinical Trials (ImPaCCT). For more information, please contact the project coordinator, Dr Tim Lockett, tim.lockett@uts.edu.au or 02 9514 4861.



Your email address please

About two thirds of our members have provided their email addresses – thanks to those who have forward them. It makes it so much easier and faster to contact you when something which may be of interest or urgency for our members come up. If you wish to confirm or update yours, please send to info@cancervoices.org.au.



CVN COMMITTEE NEWS

Your Executive Committee met on 10 June and 12 August. At the 10 June meeting, Cancer Voices "own" MP, Kathy Smith joined us. We enjoyed hearing about her new role and political life, cancer issues continuing to have a high priority.

Her Maiden Speech noted how consumer advocacy through Cancer Voices had helped fine tune her skills and community interests.



CVN ADVOCACY UPDATES

Informed consent re treatment & costs

This big issue has resurfaced and we have decided it needs real attention. It is that of getting sufficient information to make good decisions about cancer treatment, its location and any costs likely to be incurred - written so it can be considered and discussed with others. Cancer Voices has developed a Position Statement about this which is now on the website.

Survivorship Statement

Cancer Voices understands that there will soon be considerable good news to report on the development of a national framework for Survivorship, led by Cancer Australia. We are delighted that Cancer Australia has responded so positively to this consumer initiative.

Access to New Cancer Drugs Inquiry

The report and recommendations of this important Senate Inquiry have been delayed until 9 September, so we can't bring you the latest news. After that date, visit: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Cancer_Drugs/

Medical Cannabis – the Lambert Initiative

The Lambert family has given the University of Sydney \$34m towards medical cannabis research. "Our vision is to make Australia a world-leader in researching how to realise the powerful medicinal potential of the cannabis plant," said Barry Lambert, who together with his wife Joy, has funded the [Lambert Initiative](#). "The experience of our granddaughter, who suffers debilitating epilepsy, has opened our eyes to the extraordinary possibility of cannabinoids treating not only her condition but a range of chronic illnesses that often don't respond to conventional treatments".

Cancer Voices has formally welcomed this generous move. We understand that Lucy Haslam, is on the Board, which will ensure that the clear consumer voice is well and truly heard!

Regulator of Medicinal Cannabis Bill 2014

The Constitutional and Legal Affairs Committee tabled its report into the Regulator of Medicinal Cannabis Bill 2014 and has unanimously recommended that the Bill be passed into law. See [http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal and Constitutional Affairs/Medicinal Cannabis Bill/Report](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Medicinal_Cannabis_Bill/Report).

Cancer Voices wrote to leading MPs and Senators within the Parliamentarians Supporting Cancer Causes group to support the Inquiry's recommendations and made a statement to the media. We have also spoken with Dan Tehan MP who is co-Chair of this group. Mr Tehan has assured us of Government support for the Bill. We contacted the 30 group consumer related groups within the Australian Cancer Consumer Network to ask that they contact parliamentarians to support the Bill.

Travel insurance

Cancer Voices had a productive meeting with the Insurance Council of Australia's on 5 August. We welcomed their offer to contact their members in the first instance to see what is currently on offer for cancer patients – those who are living with their cancer and those who have had no recurrence from some time. We pointed out that we could be quite a sizeable market, and that many of experience no recurrence, or are living well with their cancer. Watch this space.

Access to early superannuation

Super fund members who are terminally ill can now access their savings earlier under new laws that came into force in the first week of July. The change in regulation allows people to apply to withdraw their super if they have a life expectancy of two years or less. This is a big improvement on the previous change, brokered by consumers including Cancer Voices, which only allowed a 12 months life expectancy.

NSW Cancer Plan

The Cancer Institute NSW has advised that Cancer Voices, as a recognised stakeholder and contributor, will be consulted about the new draft Cancer Plan in October.

No patents on human genes campaign

The decision regarding the Appeal to the High Court by Maurice Blackburn & Yvonne Darcy has not yet been handed down. It is awaited with baited breath!

Consumers attending Cancer Conferences

The Clinical Oncology Society of Australia (COSA) has turned down our request for financial assistance to enable registration free places to volunteer cancer consumers for attendance at the COSA Annual Scientific Meetings (ASM). However, we have been offered student rates and three of us will be attending the Hobart COSA ASM in November. This conference is an excellent opportunity to update ourselves about current cancer research of all kinds, and to meet Australian, and some international, key players. We have also submitted two Abstracts for consideration.

Meanwhile, Cancer Voices South Australia has alerted us to a website which promotes the concept of the value of consumer inclusion at conferences, internationally – See www.patientsincluded.org.au.

More advocacy news in Cancer Voices Australia NEWS UPDATE – see page 7-8.



CONSUMER REPS PROGRAMS

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 this or any other organisation. These requests are usually made by cancer professional organisation and service planners.

Training: Please check the Noticeboard (Pg 2) for information about the next Consumer Advocacy Training (CAT) course to be held by the Cancer Council NSW on 13 & 14 November – your last chance this year. Cancer Voices welcome several new members following the July CAT course and looks forward to introducing them to our advocacy programs and to hearing their ideas about issues and activities.

Cancer Voices understands that members of the **Cancer Institute NSW's (CINSW)** new Consumer & Community Advisory Panel were invited to a training /orientation day on 3 August.

Sally Crossing and Elisabeth Kochman, as Chair and Deputy Chair of Cancer Voices, met with senior CINSW staff in mid-June and CINSW news of interest to people affected by cancer will appear in our newsletter again. See page 6.

Cancer Patient Experience survey – a number of us, at least ten, have volunteered to complete this major CINSW survey about the experience of cancer and its treatment.

Some major consumer rep positions

Cancer Australia has asked Cancer Voices to coordinate nominations for appointment to CA's Intercollegiate Advisory Group, two from the Cancer Voices family and two from the Australian Cancer Consumer Network – from which a total of two appointments will be made.

We have also received an invitation to nominate to the National Cancer Expert Reference Group. See page 8.

Cancer Voices' Executive Committee member, Lee Hunt, has become a member of the Advisory Board for Australia's first Centre of Research Excellence in Cancer and Indigenous People and David Campbell has joined the Royal College of Pathologists Lay Committee. Sally Crossing is enjoying her time on the Faculty of Radiation Oncology Council (RANZCR) and another Cancer Voices member, Rosanna Martinello is now a consumer representative on the National Cancer Expert Reference Group, as well as chairing the Cancer Council Australia's "ConsumersCan" committee. All part of the "voices" being herd!

The **Oncology Social Workers Australia (OSWA)** has invited Sally Crossing, for Cancer Voices, to give a presentation to its national conference in Sydney on 11 September. This will be a good opportunity to alert oncology social workers – those very important links in the care coordination chain – of our areas of interest and how we may assist their work with people affected by cancer.



CONSUMER INVOLVEMENT IN RESEARCH (CIR)

A very quiet time of the year for our CIR Program, while researchers are busy working on currently funded studies and have yet to work up the next batch for funding applications. Many of our CIR nominees are have a very rewarding time assisting "their" researchers with the consumer view. **Next training day is 20 Nov.**

Thanks again to all the active trained consumers!

To record the ideas behind and the development of Cancer Voices' Consumer Involvement in Research (CIR) Program, Sally Crossing has written a short paper. This has been accepted for publication in Cancer Forum, the journal of the Cancer Council Australia, and will be published in its November edition, ensuring a wide readership. We will re-print it in the December Cancer Voices Newsletter, and load it onto our website. We believe it's important for major successful initiatives such as the CIR Program to be captured for posterity – at least so that other States, agencies, funding bodies and research institutions can learn from our experience.

Meetings

- Cancer Council NSW, Joint Executives, 17 June
- Cancer Council NSW: CIR meeting 24 June
- Cancer Institute NSW, 17 June & 11 Sept
- PBAC: Biosimilars Meeting, 7 July
- RANZCR Faculty of Radiation Oncology Council, 17 June & 4 Sep
- Lymphoedema Action Alliance, 20 July
- Insurance Council of Australia, 5 Aug

Media

- Cancer Screening debate, SMH 17 & 18 June (online and print) and Oncology Network Newsletter 20 June.

Submissions

- Position Statement on Informed Consent
- Health & Medical Research Future Fund Bill
- Priorities for Guideline Topics 20015, AHMAC

Conferences / Forums/ Events

- Sydney Ideas Health Forum, USyd 29 July – Cancer Screening Debate
- Oncology Social Workers Conference, 11 September
- Two Abstracts submitted to COSA ASM Conference Nov 2015

Cancer Screening: Are we harming the healthy?

One of three Sydney Ideas Health Forums for 2015 brought together key players and interested people to discuss the pros and cons of cancer screening. As a result of Sally Crossings' opinion pieces published in June, Cancer Voices was invited to provide the consumer view, and Roberta Higginson spoke for us at the University of Sydney on 29 July. Her outline of views follows.



The photo above shows the panel (second left to right):

Dr Alexandra Barratt: People need to make informed choices in deciding if screening is right for them. Breast Screening results in over-diagnosis and results in the over treatment of some women.

Dr Warwick Lee Radiologist: Has done significant work to improving the quality of mammography in Australia. He has developed programs to improve the accuracy of diagnosis within BreastScreen.

Dr Liz Marles: Works with fellow GP's to promote the importance of GP involvement in screening decisions and to provide information and support to patients.

Roberta Higginson: Is involved as a consumer representative in BreastScreen at state and national level. She believes in the importance of an early diagnosis followed by multidisciplinary care to determine Best Practice treatment options for the patient to consider. Evidence shows this improves survival rates and reduces the severity of treatment required.

Dr Glen Salkeld - Health economist. Some screening, specifically BreastScreen, is not cost effective. But our society expects it. Screening for prostate cancer has not been confirmed as being best practice.

Report form the National Aboriginal and Torres Strait Islander Framework - National Forum on 23 June 2015

Australia's record of cancer survival is one of the best in the world, but a similar level of benefit has not extended to Aboriginal and Torres Strait Islander people. The poorer survival rate from cancer, despite similar incidence, suggests however that better outcomes should be achievable.

A draft National framework has been developed to provide guidance for the concerted effort required to address this disparity in cancer outcomes. It aims is to identify the priorities that most require attention so as to improve the cancer outcomes for Aboriginal and Torres Strait Islander people. Developed by Cancer Australia in partnership with Menzies School of Health Research, the Framework was informed by two major strands of work: a review of evidence and stakeholder consultations. Several hundred people from across Australia provided input; a high proportion of participants were Aboriginal and Torres Strait people, including many directly affected by cancer.

A range of different consultative approaches were used to reach these stakeholders, including Face-to-Face forums, online surveys and online discussion boards. The National Forum enabled feedback from community leaders and advocates, health professionals, non-government organisations and researchers on the draft Framework, enabling meaningful engagement to address the disparity of outcomes for indigenous people and guide future directions in cancer control at all levels.

Jeannie Ferris Cancer Australia Recognition Award for Bridget Whelan

Bridget Whelan (right) is the successful recipient of Category One of the Award, open to those with personal experience of gynaecological cancer either as a woman with a diagnosis of gynaecological cancer, a community member, or family member or carer who has made an exceptional contribution to supporting women affected by gynaecological cancer. Diagnosed with ovarian cancer in 2010, Bridget's commitment to improving outcomes for women is evident in her work as a consumer advocate and involvement with leading cancer organisations in Australia over a number of years.



This Award is named in honour of the late Jeannie Ferris, former Senator for South Australia who was passionately committed to raising awareness about gynaecological cancer in Australia. Senator Ferris was diagnosed with ovarian cancer in October 2005 and died in April 2007.

Bridget Whelan was a qualified lawyer and senior adviser to several State and Federal Government Ministers. Following her diagnosis, she used her considerable professional skills in volunteer work as a consumer advocate, ensuring that the consumer experience informs cancer research, information, policy and care.

Ms Whelan's commitment to improving outcomes for women with ovarian cancer is also evident in her extensive and diverse work for a number of organisations, throughout her treatment and recovery cycles. These include: Ovarian Cancer Australia; the Australia and New Zealand Gynaecological Oncology

Group; **Cancer Voices**; and Cancer Institute NSW. Ms Whelan has also provided consumer input into research programs for Calvary Hospital, University of New South Wales, Garvan Institute, Westmead Hospital and the Peter MacCallum Cancer Centre.

Lee Hunt

Cancer Institute NSW Update

Cancer Voices NSW welcomes back this occasional update from the Cancer Institute NSW (CINSW), focussing on projects and matters of interest to people affected by cancer.

Canrefer – Website Upgrade

Canrefer, the online cancer services directory for NSW and ACT, is undergoing an upgrade. The website allows people affected by cancer and clinicians to search for conveniently located, tumour-specific services. The upgrade will make it easier to search for cancer services and specialists, using Google maps to allow people to search for hospitals or cancer services close to them, as well as improved functionality making it easier to use and keep up-to-date. It is scheduled to Go Live in September 2015 – visit www.canrefer.org.au.

NSW Cancer Patient Experience Survey Project

This Project aims to drive improvements in the quality of cancer care for people in NSW through the collection and feedback of patient experience information. We have pre-tested the UK/NHS Cancer Patient Experience Survey with 18 consumers in order to adapt it for use in NSW and the survey will be piloted later this year across four sites in NSW. All going well, the survey will then be administered across the state on a regular basis. The information obtained from the surveys will help to guide service improvement initiatives to improve the experience of cancer care.

Patient Reported Experience Project

The PROMPT-Care (Patient Reported Outcome Measures for Personalised Treatment and Care) Pilot Project is being led by Professor Afaf Girgis (Ingham Institute for Applied Medical Research) and puts in place the foundations for improving the experience of people living with cancer during the treatment and survivorship phases of care.

The project will pilot an e-health system to collect, analyse and report on patient reported outcomes (physical, social, emotional and practical needs), provide tailored self-management information and empower people to take an active role in decision. It is

funded by the CINSW with seed funding also provided from BUPA Health Foundation.

Patient Navigation Project

People diagnosed with cancer are thrust into the health care system with little or no experience with how to navigate through it, and often turn to the internet for assistance. Although there is a plethora of reliable information on the internet, the sheer volume can be overwhelming and there is also the issue of sorting the reliable information from the not so reliable.

The Patient Navigation Project aims to provide quality information at the right time, supporting patients to make informed decisions, and reduce the anxiety associated with the uncertainty of what happens during and after cancer treatment. In consultation with people affected by cancer, the project will develop a website that provides links to trusted sources of

information which have been assessed for accuracy and appropriateness. Launch date is planned for late 2016.

Innovations in Cancer Treatment and Care Conference 15 October

This is a free, annual event hosted by the CINSW, providing an opportunity to hear about innovations in cancer treatment and care underway within NSW and to learn from experts in the field. The keynote address will be delivered by Professor Thomas Feeley, Head of the Institute for Cancer Care Innovation at The University of Texas' MD Anderson Cancer Centre, where he leads work studying new and existing models of cancer care delivery and reimbursement. Registration for the conference is now open – visit www.cancerinstitute.org.au/innovations to secure your place!



Cancer Voices Australia NEWS UPDATE - August 2015

Priority issues for Australians affected by cancer

As facilitator of the Australian Cancer Consumer Network, Cancer Voices has developed a survey using Survey Monkey to ask cancer consumer organisations about their main generic priorities. It will be sent out shortly and results will be used to inform our representatives in the lead up to the coming federal election, and to advise cancer agencies and charities what differences people affected by cancer in Australian want to see made.

Better access to cancer drugs:

The Senate Inquiry report on Availability of new, innovative and specialist cancer drugs in Australia is now due 9 September. It will be accessible via: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Cancer_Drugs

Informed consent for cancer treatment and costs

Responding to concerns raised by consumers, CVA has a released Position Statement calling for regular, written informed consent for both treatment and costs of treatment, if any. See CVA website.

Implications of chemo under-dosing in SA

Media interest in this case has highlighted the need for quality & safety standards for the delivery of chemotherapy in both public and private sectors.

Travel insurance for cancer patients

CVA has met with the Insurance Council of Australia to outline the problems faced by people affected by cancer (experienced previously or currently) when trying to arrange travel insurance, and ways these might be addressed. So far, the ICA's interest in addressing this issue is very encouraging.

Regulator of Medical Cannabis Bill 2014

Following the positive recommendations of the Senate Inquiry, Cancer Voices supports the introduction and debate of this Bill ASAP. CVA has approached the

Australian Cancer Consumer Network, all members of the Parliamentarians Supporting Cancer Causes (Friendship Group), and selected Senators to support its passage. We have welcomed the \$34m funding of the Lambert Initiative for medicinal cannabis research at USyd.

Cancer Screening: Are we harming the healthy?

Cancer Voices was invited to provide the consumer view on a panel for University of Sydney's *Sydney Ideas Health Forum* on this topic on 29 July. Roberta

Higginson was our nominee and held the fort strongly for us.

Medibank Private’s proposed changes to PHI:

Cancer Voices has written to Medibank Private to express our concern about coverage changes at Canberra’s Calvary Hospital, and potentially at other private hospitals, especially as they affect cancer patients who may have to return within 28 days of release.

CVA contributions to current Reviews:

PBAC’s Review of biosimilar drugs regulations; Senate Inquiry into Chronic Disease, the Medical Research Future Fund Bill and the Medicare Benefits Schedule Reviews.

Consumers attending cancer conferences:

a rebuff from COSA, but CVA is pleased to note the arrival of an international movement, Patients Included see www.patientsincluded.org which establishes a Charter to support the participation of consumers in conferences which are associated with relevant health care. Meanwhile, CVA has offered two consumer related Abstracts to the COSA ASM Conference in November.

Jeannie Ferris Cancer Australia Recognition Award:

received by Cancer Voices’ Bridget Whelan for an exceptional contribution to supporting women affected by gynaecological cancer, through her commitment to improving outcomes as a consumer advocate. Congratulations, Bridget!

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



THANKS!

Cancer Voices NSW greatly appreciates the assistance given by Cancer Council NSW for printing & posting Cancer Voices Newsletters.

THANKS also to the Cancer Voices Newsletter Team for labels, content & design.

Contact CVN

PO Box 5016 Greenwich NSW 2065 E: info@cancervoices.org.au

W: www.cancervoices.org.au

STOP PRESS: National Cancer Expert Reference Group – Seeking a Consumer Advocate

Expressions of interest are welcome from individuals who are capable of representing the viewpoints and concerns of Australian cancer consumes. Please send an outline of your skills and experience (2 pages max) to the NCERG Secretariat by 30 September NCERGSecretariat@health.gov.au, or post to NCERG at MDP 703, Dept. of Health

GPO Box 9848, Canberra ACT 2601. NCERG is a high level, expert national cancer forum.

NCERG has developed a National Cancer Work Plan to improve cancer care and outcomes.

NCERG meets face to face twice per year plus two teleconferences. Attendance costs are covered.