

MESSAGE TO MEMBERS

Cancer Voices has been looking at our New Year's resolutions – based on responses to our 2015 Issues Survey. We have a good set of priorities to work on with decision-makers and key players.

And the beauty is that these are the priorities of real people who have, or are, experiencing cancer – not academics, charities or government agencies. Ours is the essential perspective!

AGM and Annual Report 2015: To gain an idea of where we stand at the beginning of the year, please check my Annual Report in this Newsletter and presented to the AGM on 24 Feb. Our Executive Committee line-up for 2016 is listed on page 2.

Thanks to those Executive Committee members who have returned to serve the interests of people affected by cancer, and thanks to the newbies – we need your invigoration just as much.

Role & range overview: Cancer Voices, entering its sixteenth year, feels well positioned and recognised as the state's preeminent (in fact, only), independent and volunteer voice for people affected by any kind of cancer. As you know, we don't get involved in specific cancers' issues, unless their groups seek our help or advice. We focus on the bigger generic issues, and will continue to do so. Having a close association with both Cancer Voices Australia and the Australian Cancer Consumer Network means we can also contribute to and support advocacy on issues well beyond NSW.

I have been invited to put the Australian cancer consumer view at a Health Forum "War on Cancer", held annually by The Economist weekly newspaper, held in Singapore, which brings together leaders in cancer control from across Asia and SE Asia. It is the first time they have included a consumer representative, and we must make sure not the last. The National Institute of Cancer in France has also interviewed me about consumer views on access to new cancer drugs. The range broadens!

New developments in cancer treatment: My own cancer journey continues to throw up more decisions, as the last two oral chemos have now failed. In January, I had a liver biopsy so that some current tumour tissue could be fully molecularly profiled and collated against existing cancer drugs by a specialist company in America. It's part of the pharmacogenomic approach to cancer treatment, which we in Cancer Voices have been looking forward to for many years. I am also signing up to the SIR Spheres treatment, tiny radioactive balls to zap the liver metastases. A Medicare rebate is available for colorectal liver mets, but not for breast cancers which would benefit – another advocacy issue for us. New drugs on clinical trials may be a further option after that. None of this was on the offer when I was first diagnosed with early breast cancer 21 years ago – access to innovative treatment must stay high on our list!

Funding important priorities: A challenge of this year is to identify some issues we know which need research, and would get up with a small amount of funding encouragement by Cancer Voices. We can now consider doing this, thanks to some special donations over the last couple of years. Let us know your suggestions via info@cancervoices.org.au – all will be considered.

Updates about Support and Information in NSW: We have invited both NSW organisations which have the potential and role to most help people affected by cancer – the Cancer Council NSW and the Cancer Institute NSW to provide snapshots on their relevant projects and service each newsletter.

Lots to look forward to in the brightening world of cancer consumer advocacy during 2016!

Very best wishes to all our readers, our members and our excellent consumer representatives.

Sally Crossing AM, Chair & Editor





CVN Committee News

Cancer Voices Annual General Meeting was held on 24 February and our Annual Report is published in this Newsletter, and on the website.

Your Executive Committee for 2016 is as follows:

- Chair: Sally Crossing AM
- Deputy Chair & Hon Sec: Elisabeth Kochman
- Committee members (elected or co-opted):
Phil Wadick, Jan Mumford, Bev Noble, Peter Brown, Roberta Higginson, David Campbell,

Bridget Whelan, Lillian Leigh, Eve Propper, Sandra O'Sullivan (Treasurer).

The Executive Committee has approved a commitment to support in a small way, a research project looking at survivorship monitoring. This topic reflects our objectives and our current priorities. If the proposal wins a NHMRC grant, our contribution will span the four years of its life. The proposal includes strong consumer engagement at all levels.



CVN Advocacy Updates

Informed consent re treatment & costs

The issue is about getting sufficient information to make good decisions about cancer treatment, its location and any costs likely to be incurred, and written so it can be considered and discussed with others. Following Cancer Voices new Position Statement on this we are pleased to say that our recommendations were taken on board by the Royal Australian & New Zealand College of Radiology's revised Code of Ethics. Cancer Voices would welcome the opportunity to talk to the other cancer-related professional colleges about doing the same.

Survivorship Advocacy

(i) Survivorship Principles Statement

Cancer Australia has begun work on the development of a national framework for the principles of Survivorship and will soon be seeking stakeholder consultation on a first draft.

(ii) Survivorship Care Plans

We note that the Australian Cancer Survivorship Centre based at PeterMac Cancer Centre in Melbourne has just released "Survivorship Care Plans: Literature Review". It examines a large number of papers on the subject to inform the use and content of such Plans. Cancer Voices has long advocated for Treatment and Care Plans to be an integral part of the cancer journey, from diagnosis onwards. This is an extremely difficult outcome to measure, and we can't help feeling that common sense should inform us that a Plan will help doctors, patients and their families to move through their "journeys" with more confidence, coordination and understanding.

(iii) International connections:

Cancer Voices has joined the National Coalition for Cancer Survivorship (NCCS) in the USA. The NCCS is supporting the Planning Actively for Cancer (PACT) Act, which ensures the development of a personalised cancer care plan, from diagnosis, through treatment and long-term survivorship. This could be an idea to adopt in Australia.

Lymphoedema Action Campaign

Cancer Voices joined the other 18 non-government organisations which form the Lymphoedema Action Alliance (LAA) to press our case for funding 62.5 new lymphoedema therapist positions in NSW as part of the 2015-16 State Budget. The LAA estimates that approximately 10,000 people are coping with lymphoedema in NSW alone, much of it caused by cancer treatment, and that there is a chronic shortage of trained therapists who can help these people. Cancer Voices has written to NSW Minister for Health inquiring about inclusion of this funding in the May Budget.

Access to New Cancer Drugs Inquiry

While this remains a top priority issue for many people affected by cancer and their advising clinicians, there has been no definitive response by Government to the Senate Inquiry recommendations. Sounds like the old "too hard" basket again. Cancer Voices continues to seek a solid response in association with Rare Cancers Australia.

NSW Cancer Data –timeliness and access

Cancer Voices continues to be concerned that NSW is behind all other states in collection and analysis of incidence and mortality data. This and difficulty of access impact badly on NSW's cancer planning.

Travel Insurance – good progress

Cancer Voices NSW met with members of the Insurance Council of Australia on 21 January. Our aim was to ask for consideration of, and possible solutions to, the different risks to be covered for (i) those who are living with their cancer as a manageable chronic disease, (ii) those who have had no recurrence from some time, and (iii) those who may be facing end of life. The meeting agreed to pursue the development of a matrix to make it much easier for consumers to find the kind of cover which best suits them. Cancer Voices is working with the ICA to develop this very necessary tool.

Medical Cannabis Campaign

United in Compassion, led by Lucy Haslam and Troy Langman, has invited Cancer Voices to take part in the second Medical Cannabis Symposium. This year it will be held in Sydney on 14 and 15 May. Last year's excellent outcome was that the NSW Premier Mike Baird made a number of announcements about funding research, and not prosecuting people who are genuinely using the drug for medical purposes, including cancer patients.

Federal Health Minister, Sussan Ley MP, announced that a Bill would be introduced on 10 Feb to allow for medical cannabis cultivation through a national scheme. Labor and Greens support is expected. Cancer Voices has supported this Bill since first drafted by the national Greens.

NSW Cancer Plan

We await news as to whether Cancer Voices' response to the Cancer Institute NSW's Consultation draft NSW Cancer Plan 2016-2020 has been considered, and hopefully incorporated. In that response, we called for a number of inclusions, including reference to the role of consumer engagement, the publication of more recent cancer statistics (the draft uses 2010 stats), and more relevant outcome indicators.

Cancer Workforce Issues

(i) Cancer Nurse Coordinators

During 2016, Cancer Voices plans to re-engage with Government and the Cancer Institute about the funding and number of these positions throughout the state, due to reports that their numbers have been falling in some NSW cancer centres, since the CINSW action to no longer directly fund positions.

(ii) Oncology Social Workers in NSW

The NSW Minister for Health has responded to Cancer Voices letter of concern about reviewing the short contract status of oncology social workers. As usual she says that how CINSW support is spent is the business of Local Health Districts. Not good enough, we say.

Consumers Included – a logo “tick”?

We continue to encourage professional colleges and other organisations to sign up to the international charter developed by *Patients Included*, which gives them a big public tick for doing so. We are discussing establishing an Australian version, to be called *Consumers Included* in partnership with other health consumer groups. It would identify those colleges and organisations which include consumers in their informational/ scientific events & conferences, as well as at decision-making levels.

Truth & Timeliness in Research

Cancer Voices has decided to support the Alltrials (see www.Alltrials.net) international campaign that works to see all clinical trials register with a central agency, report on time and report their results, whether positive or negative. This has been the topic of much discussion in the major peer reviewed medical journals. Legislation was passed in the USA in 2007 but has not been implemented in any meaningful way. This is seen as a disservice to patients, to funders and to the value of research undertaken and funded. It is especially important for people with cancer as many clinical trials are cancer related.



Contact CVN

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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. These requests are usually made by cancer professional organisations and service planners.

Training: A Consumer Advocacy Training (CAT) course was held by the Cancer Council NSW in February, and new “graduates” who choose to become Cancer Voices members are most welcome.

We will advise further 2016 dates in our June newsletter.

Cancer Patient Experience survey – A number of us were invited to complete this major CINSW survey about measuring the experience of cancer and its treatment. This was followed by a very productive consumer consultation meeting on 22 October. The final measurables will be used in the public hospital system from May 2016, via the Local Health Districts. We hope that measuring the cancer experience will also take place in the private sector in due course (some already do their own).



Consumer Involvement in Research (CIR)

There has been much activity this year already in our CIR Program. CIR Database Manager and chief “matcher”, Lee Hunt, has been responding to a rush of requests as researchers put their grant applications together before the March cut-off date. Cancer Voices matching service has provided 32 consumer nominees for 21 research projects and committees during the December to February period. Ten consumers are presently on new projects that have been given funding for 2016. The projects cover many areas of cancer research, including combination drug therapy, activation of a patient’s own immune system to control cancer cells and joint study with English researchers.

Thank you to our consumers who have readily undertaken this very important role in cancer research.

A Consumer Involvement in Research Alliance?

At the **Australian Cancer Trials Alliance Workshop** on 7 November, the consensus was agreement to explore a Consumer Involvement in Research Alliance. Cancer Voices has offered to contribute a small amount of seed funding to establish the Alliance, but has yet to hear of any progress towards a start-up.



The Voices being heard

Meetings

- CVN / CCNSW Joint Execs Meeting, 20 Jan
- Insurance Council of Aust, 21 Jan

Submissions

- NSW OHMR Biobanking Consultation French National Cancer Institute: Innovative cancer drugs review

Media

- Medical imaging & Medicare, with CHF, Feb

Conferences / Forums/ Events

- The Economist War on Cancer, 17 Mar, Singapore: S Crossing as consumer speaker

NEWS from the Cancer Council

Accommodation Services: Cancer Council NSW has been working to relieve some of the stress of travelling for cancer treatment by delivering improved accommodation options.

Partnership: Cancer Council NSW has entered into partnership with Accor Hotels, which now provides reduced-rate hotel rooms for all people in NSW who need to travel for treatment. This complements the current Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS).

Community-based accommodation: We are also committed to an ongoing investment in and partnership with 10 community-based accommodation facilities across NSW.

One example is Lilier Lodge was established in 2004, features 20 double rooms, and is closely situated to the Riverina Cancer Care Centre and Wagga Wagga Base Hospital. . With joint venture partner CanAssist, works are about to commence a refurbishment to Lilier Lodge.

Legal, Financial and Workplace assistance for people affected by cancer across Australia

Cancer Council assists people affected by cancer with legal, financial planning, small business accounting and workplace issues through the Cancer Council Pro Bono Program. This connects with professionals – lawyers, financial advisers, HR and recruitment specialists and small business accountants – who volunteer their time to give advice to eligible clients on issues which have arisen as a result of the cancer diagnosis.

Since 2010, Cancer Council's Pro Bono Program has assisted over 6,800 families affected by cancer across Australia with free advice and assistance on a range of legal, financial and workplace issues.

For more info, call Cancer Council 13 11 20.

Consumer representation within the CCNSW?

Cancer Voices is seeking an update on how and where consumers are involved within the Cancer Council NSW's own committees and projects. We will advise on receipt of this update.

Cancer Institute NSW Update

eviQ – Patient information sheets in English and 9 other languages: eviQ Cancer Treatments Online is the CINSW's web-based information portal, providing free access to the latest evidence-based, best practice cancer treatment protocols and other treatment-related information. A new range of patient information sheets have been released, translated into 9 languages: Arabic, simplified and traditional Chinese, French, Greek, Italian, Korean, Spanish and Vietnamese. Visit www.eviq.org.au/PatientInformationSheetsTranslated.aspx

Canrefer Update: The Canrefer website enhancement went live in December 2015. Canrefer lists specialists who are validated members of multidisciplinary teams. The Canrefer team works with cancer services to update their information and MDT specialist membership on Canrefer every 6 months to ensure it remains a reliable resource.

Aboriginal Community Liaison: CINSW has appointed Marita Maher to the Aboriginal Community Liaison role within Cancer Services & Information - Relationships & Change team. She will provide leadership and progress elements in the Cancer Plan that are pertinent to the ATSI population in NSW.

NSW Cancer Patient Experience Survey Pilot Project:

The pilot survey was completed by 1,219 people (response rate 55%). The overall aim of the survey is to capture information about patient experience across the care continuum. The pilot data is now being evaluated.

Cancer Patient Experience Indicator Development: The Cancer Institute NSW warmly thanks the consumers from Cancer Voices NSW who participated in the formation of the patient experience success factors by completing the Delphi study.

eviQ Education: eviQ Education is updating the course to train nurses to administer antineoplastic drugs to patients (by Nov 2016). This course is run in over 280 cancer centres across Australia and some in New Zealand.

CINSW Consumer and Community Advisory Panel Project: Operating for 12 months, with 40 members, the panel has contributed to over 15 projects including reviewing patient information sheets; sitting on project Advisory Groups; participating in focus groups and surveys; as well as reviewing the NSW Cancer Plan 2016-2020. We acknowledge the importance of continuous community engagement and look forward together to working on a range of initiatives in 2016.



Cancer Voices NSW ANNUAL REPORT 2015

It is with pleasure that I present the Cancer Voices NSW 2015 Annual Report, as our fifteenth year ends. 33 **Highlights** include marking the first decade of our ground-breaking Consumer Involvement in Research Program (CIR) 2005-2015. This we did via two major conference presentations, and a published article in *Cancer Forum*. A second highlight was organising and analysing a survey of issues for people affected by cancer, in preparation for a possible federal election and to present to decision-makers.

Cancer Voices NSW (CVN) continued to be strongly engaged in state and national level activities, the latter through Cancer Voices Australia (CVA) and the new Australian Cancer Consumer Network (ACCN), facilitated by CVA.

Achieving our goals: Cancer Voices worked to its prime function of providing an effective voice for people affected by cancer by pursuing standing advocacy issues and addressing new ones as they arose. During the year we made sure that voice was heard on the following issues (more details contained in our quarterly newsletters, Nos 58-61 inclusive, posted on www.cancervoices.org.au)

- *Survivorship and coordination of cancer care – best practice standards*
- *Continuation & expansion of cancer nurse coordinator positions*
- *Legalizing access to medical cannabis*
- *Access to high cost cancer drugs & security of supply*
- *Access to Lymphoedema services and garments*
- *Support for consumers attending cancer conferences*
- *Best practice for Practice standards for medical oncology*
- *Up to date and comprehensive NSW cancer statistics.*

- *Informed consent for treatment and its costs, upfront*
- *Travel insurance of people affected by cancer*
- *Greater access to palliative care services*
- *Adequacy of cancer workforce, esp. cancer nurse coordinators and oncology social workers*

Cancer Voices Wins: We especially welcomed the NSW Government’s decision to remove co-payments for chemo in NSW public hospitals, for which we had advocated strongly. During the year there were also a number of Government and research moves towards enabling better access to medical cannabis. We were delighted, after several years’ engagement by Cancer Voices, by the High Court decision to remove the ability to grant patents over human genetic material. We welcome Cancer Australia’s response to our call for national Survivorship Principles. And we congratulated Kathy Smith MP, previous Cancer Voices Chair (2010-2012) on being elected to the NSW Parliament – our “voice” in the House!

Award for Excellence in Cancer Consumer Advocacy 2015; Cancer Voices recognises those advocates and consumer representatives who demonstrate excellence in their activities. The Award was presented to Bridget Whelan at the Cancer Council’s Research Awards presentation on 30 April.

Working with stakeholders: CVN nominees and the organisation itself worked with the wide range of “cancer world” stakeholders listed in previous reports, at both state and national levels. We have initiated a “Consumers Included” Tick for organisations which include cancer consumers on their principal decision-making committees and support attendance at cancer related conferences. This is inspired by the international program “Patent’s included” which Cancer Voices supports.

Consumer Representation and Training: Two Consumer Advocacy Training (CAT) courses were held with Cancer Council NSW (CCNSW) in July and November, and their graduates invited to join Cancer Voices. One Consumer Involvement in Research (CIR) training course was held in November with the CCNSW. The latter provided an extra 19 new “graduates” to support our CIR matching program for researchers seeking to work with informed consumers, now a requirement for most grant approvals. Our website and support process continue to work well, ably managed by Bridget Whelan throughout the year.

The Written Word: Quarterly 8-12 page newsletters were published during 2015 and mailed in hard copy to members and stakeholders as well as being posted on the website for wider access. The December issue was our 61st Newsletter. They contain fuller details about Cancer Voices’ 2015 activities and achievements. Cancer Voices NSW is also responsible for the production of two-monthly Cancer Voices Australia *News Updates*. Major submissions and reviews were posted on the website, those related to national issues being accessible via the Cancer Voices Australia website. Cancer Voices developed two conference posters, presented at the Clinical Oncology Society of Australia ASM and the NSW Cancer Institute’s Innovations Conference. To engage in discussion and debate on current issues for people affected by cancer, Sally Crossing had a number of short papers published during the year, and Website and Facebook updating continued.

Speaking Out: Members continued to attend workshops, seminars, conferences during 2015, contributing the consumer view, taking the opportunity to network and to keep up to date and knowledgeable in the cancer arena. CVN representatives continued to give invited addresses, to appear before related government inquiries and to contribute to media discussion.

Organisational: 2015 saw a steady increase in new membership which we welcomed warmly, sending each an info package and encouragement about joining our advocacy activity. Group members total 70, and individual membership is 365. Newsletters are also sent to 136 organisations and health professionals who want to be informed about CVN and issues for people affected by cancer.

We remain an entirely independent and voluntary advocacy organisation; our success depending on the efforts of members, consumer representatives and particularly, members of the Executive Committee. Special thanks to Sharon Pannewitz who manages our growing database very efficiently and to Kathryn Leaney, formatter extraordinaire of the newsletters. Karen Metcalfe ably keeps the website under control and up to date.

The Executive Committee met every two months at the CBD offices of UBS Investment Bank and out of session as necessary. Members this year were Sally Crossing (Chair), Elisabeth Kochman (Deputy Chair & Hon Sec) Sandra O’Sullivan (Treasurer), Bev Noble, David Campbell, Peter Brown, Roberta Higginson, Bridget Whelan, Jan Mumford and John Fullagar. 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 2015 is presented separately. The injection of funds from member group BCAG NSW has meant we can now support a few projects which we deem of optimal value to people affected by cancer, and cover Cancer Voices Australia’s core financial needs. We recognise the valuable volunteer work of members and appreciate pro bono

services such as newsletter printing and mailing by the Cancer Council NSW.

Recognition: Public recognition for Cancer Voices’ work indicates that our advocacy efforts for people affected by cancer is externally well appreciated.

Reflection and Thanks: We can’t do what we do in the interests of people affected by cancer without lots of encouragement and support. Special thanks to members of the Executive Committee and to our nominees who work in positions as consumer representatives in the decision-making “cancer world”. And of course thanks to our stakeholders and supporters who seek our views and work with our representatives. Together we can, and will continue to, make a real difference.

Sally Crossing, AM, Chair 2015

POST SCRIPT...

Lymphoedema advocacy needs your help!

The *Lymphoedema Action Alliance* (of which CVN is a member) aims for:

1. equitable access to quality lymphoedema services in NSW
2. equitable and sustainable access to lymphoedema compression garments in Australia.

However the LAA needs more people with lymphoedema willing to put their name to their story to illustrate the real needs of consumers. Please do contact us at robertahigginson@gmail.com. More info at www.actionalliance.org



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 Team who bring you this Newsletter:

Kathryn Leaney for formatting, Sharon Pannewitz for database management and labels, Elisabeth Kochman for proof reading and Sally Crossing as compiler and editor.

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 Australia wishes all our NEWS UPDATE readers a Happy New Year!

Check out the collected needs and issues identified by *people affected by cancer themselves*. Remember that to include the informed consumer view as a true “patient focus” will definitely help achieve improvements.

Cancer Voices’ Hot Issues for 2016

- *Statistics collection on ‘Stage at diagnosis’ & ‘progression to metastatic cancer’*
- *Better & affordable access to cancer drugs*
- *Fair travel insurance for cancer patients*
- *Survivorship issues: national framework, practice and research*
- *Safety & quality standards for delivery of chemotherapy in public and private settings*

Priority issues for Australians affected by cancer: top five identified by the recent survey of the 30-strong Australian Cancer Consumer Network were:

- *Getting better and quicker access to cancer treatments*
- *Greater access to clinical trials with more trials available and more funding for Australian trials*
- *Supply of and access to Cancer Nurse/ Care coordinators/Patient Navigators*
- *Access to drugs for less common cancers*
- *National registry of information about treatment outcomes*

The full report is available on request to info@cancervoicesaustralia.org.au, and will be used to inform decision-makers at all levels, including political representatives in the lead up to the next election.

Cancer Australia’s Principles of Cancer Survivorship: Cancer Voices welcomes this Cancer Australia project, after strongly advocating for it over the past year. Consumer views have been heard, and a draft set of Principles, based on an evidence (both literature and practice) review, is in development. Meanwhile, CVA has joined the National Coalition for Cancer Survivorship (USA) and welcomes the Australian Cancer Survivorship’s *Survivorship Care Plans* Jan. paper.

Consumer Involvement in Research (CIR) - matching informed consumers to researchers’ requests

Cancer Voices celebrated ten years 2005-2015 of this first-for-Australia program with an article published in Cancer Forum, and an oral presentation plus poster at COSA, both in November 2015.

Travel insurance for cancer patients: CVA had a positive meeting with several interested member companies of the Insurance Council of Australia on 21 January about the complex situation re insurance for people affected by cancer.

Consumers attending cancer conferences: Three Cancer Voices reps attended the COSA ASM Conference in November, presented on two topics and prepared a report, now posted on our website. Cancer Voices is supporting the international program “Patients Included” which gives a tick logo to those conferences and other events which fully support consumer involvement. We plan a “**Consumers Included**” tick for use in the Australian context.

International invitation: Cancer Voices will be representing the patient / consumer view for the first time at The Economist War on Cancer Forum in Singapore on 17 March.

ALLTrials.net.au: Cancer Voices has joined and lent our logo to the AllTrials campaign to promote the registration and reporting (positive and negative) of all clinical trials. We will discuss the Australian scenario with the NHMRC.

SA Chemotherapy under-dosing incident; Marshall Review released in Nov 2015:

The independent Marshall Review into the incorrect dosing of Cytarabine (once/day instead of twice/day) to ten patients with acute myeloid leukaemia in 2 public hospitals has been released.

A pdf copy of the report is available at <http://www.sahealth.sa.gov.au/wps/wcm/connect>.

Issues including protocol development review of governance procedures and effective communication and dissemination of important information to staff might be relevant reminders to the broader oncology community. Collating national learnings about best ways of supporting the patients and their family affected by incidents could also be considered.

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

