

## MESSAGE TO MEMBERS

2015 has begun with a bang, several in fact, which woke us up from our summer holiday mode.

Some were at state and some at the national level.

Close to home, we have on advice, reactivated our *NSW Election Wish List* by sending it to the State Directors of the contending parties. We hope to be able to provide their replies in this Newsletter, but if not to hand in time – they will be uploaded to the CVN website.

Cancer Voices is once again in touch with NSW Directors of Cancer Centres within the LHDs, and two way engagement is underway. We welcomed the news that Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) rebate rates are to be increased – especially in relation to accommodation.

However, there is to be only slight increase in petrol rates and no news at all about enabling country patients to participate in clinical trials away from home.

We have made a substantial submission to the Senate Community Affairs References Committee Inquiry: *The*

*availability of new, innovative and specialist cancer drugs in Australia* and a number of other Reviews and Inquiries (see CVA Feb NEWS UPDATE on page 6) which have important ramifications for people affected by cancer.

The opening of the Chris O'Brien Lifehouse cancer operating theatres and 125 beds was a gala event on 13 February. A bipartisan affair, it was attended by the Prime Minister Tony Abbott, Kevin Rudd, Tanya

Plibersek, Premier Mike Baird and NSW Health Minister Jillian Skinner – not to mention Cancer Voices NSW represented by Bev Noble and me. Bev is our nominee to two major Lifehouse Committees. This is now a truly comprehensive Cancer Centre with all cancer services on one site.

Cancer Voices held its Annual General Meeting on 11 February. I welcome the excellent team who will guide us through another great year of cancer consumer advocacy – details on page 3.

Best wishes to all

Sally Crossing AM, Chair



*Everyone was at the Chris O'Brien Lifehouse Cancer Centre opening on 13 Feb 2015*



# CVN Notice Board



## Consumer Advocacy Training 2015 – 25 & 25 July (Sydney)

The Cancer Council NSW will be holding at least four “CAT” courses during 2015, in Sydney and regional NSW. These are open to CVN and community members. Visit the Cancer Council's website for dates and locations

The two day workshops provide 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](mailto:advocacy@nswcc.org.au)



## CINSW Consumer & Community Advisory Panel

The volunteer Consumer & Community Advisors will form a panel to provide advice on the Cancer Institute NSW's projects which have impact for people with cancer, their carers and the wider community.

For information about making an **Expression of Interest**, go to the CINSW website [www.cancerinstitute.org.au](http://www.cancerinstitute.org.au) or contact Peter Murray at [peter.murray@cancerinstitute.org.au](mailto:peter.murray@cancerinstitute.org.au) or on (02) 8374 3525. Cancer Voices encourages members to register their interest. This is a long awaited opportunity for consumers to have a say about CINSW projects and policies.

*NOTE: Those CVN members who have provided us with an email address will have received the original 3 Feb invitation to Cancer Voices from the CINSW.*



## NSW Cancer Services – how you can help them

Cancer Voices is looking for CVN members who live in the various NSW Local Health Districts (LHD) and may be interested in putting the consumer view to their LHD Cancer Services. If you would like to be active at the local level where cancer services are offered, please let us know.



## Your email address please

For faster contact when something which may be of interest or urgency for our members comes up, we really need your current email address. Please send to [info@cancervoices.org.au](mailto:info@cancervoices.org.au).



## Status re Access to Medical Cannabis

Information about the NSW Government's **Terminal Illness Cannabis Scheme (TICS)** is available at: <http://www.nsw.gov.au/tics>.

Information about the medical cannabis clinical trials is available at: <http://www.health.nsw.gov.au/cannabis/Pages/clinical-trials.aspx>.

Cancer Voices has been invited to provide feedback on these. Please visit the links and send any comments you may have to: [info@cancervoices.org.au](mailto:info@cancervoices.org.au).



## CVN COMMITTEE NEWS

Cancer Voices held its Annual General Meeting on 11 February. 2014 Chair, Sally Crossing presented her Annual Report, which is published in this Newsletter. The new Executive Committee for 2015 was duly elected.

**Chair:** Sally Crossing AM

**Deputy Chair & Sec:** Elisabeth Kochman

**Treasurer:** Sandra O'Sullivan

**Committee Members:** Bev Nobel, Jan Mumford, Peter Brown, Bridget Whelan, John Fullagar and Roberta Higginson.



This great combination of experience in cancer consumer advocacy and a broad range of cancer experiences will be supplemented by some co-opted members who are interested in helping us with our work for and with people affected by cancer in our

State and beyond. We are keen to ensure that our advocacy activities are distributed amongst those whose skills and interests fit well with Cancer Voice objectives.

Cancer Voices is always keen to hear from members who would like to be more involved in our advocacy, consumer representation (ie representing cancer consumers' needs and views) and in working with researcher's projects.

### **Award for Excellence in Cancer Consumer Advocacy 2015**

This will be presented to a most deserving recipient at the Cancer Council NSW Research Showcase night on 29 April. Our June Newsletter will have a full report.

### **Annual Issues Survey**

Thanks to those CVN members who sent us their completed blue insert forms (Dec Newsletter). Your suggestions for current and long-standing issues which need attention are much appreciated. We also receive issues from our online New Members forms – both sources inform our direction and keep us on track. Keep them coming at any time of year!



## CVN ADVOCACY UPDATES

### **NSW Election 28 March 2015**

Cancer Voices NSW wrote to the State Directors of six political parties with a rather full list of questions to which we would like answers if possible. Their answers will give people affected by cancer a good guide as to how the contenders would deal with the issues raised.

Our questions are:

- Should all cancer treatment centres, public and private clinics be required to be accredited for standards of clinical care?
- Will you mandate Clinical Practice Standards for Radiation Oncology and Medical Oncology in NSW?
- Do you agree that public cancer patients should not have to face cost add-ons, especially for chemotherapy treatment?
- What is your view on the need for equity in access to palliative care services, with greater funding than is available now?
- The Government's good new end-of-life care packages should be available State-wide. Will you commit to ensuring this?

- The uptake of these end-of-life care packages and their success or failure is entirely dependent on the capacity of each palliative care service. Will you commit to enhancing the capacity of palliative care services State-wide, especially in rural and regional NSW?
- Many cancer patients are transferred to aged care facilities if they need ongoing care or don't die quickly enough in acute hospitals and palliative care units. Will you commit to increase the availability of specialist palliative care to aged care facilities?
- Co-ordination of cancer care: cancer patients recommend the introduction of guidelines to ensure clarity re what services should be provided and what can be expected. Will you undertake the development and implementation of such guidelines?
- Patient-held cancer treatment and care plans will improve efficiency and outcomes: what is your view on requiring these be introduced?

- The condition of Lymphoedema needs greater acknowledgment and access to effective treatment – do you support the development and adoption of guidelines which clarify best practice treatment?
- Cancer patients want cancer research to be more focused on personalised medicine and targeted therapies: do you commit to supporting this as a research priority?
- Will you support a conscience vote to legalise medical use of marijuana for the terminally ill? What is your position on this issue?
- NSW Cancer statistics are now very outdated; the latest are from 2008. Will you seek a way to overcome the problems involved?
- Is the money spent on cancer in NSW spent most effectively (ie public cancer services and the Cancer Institute NSW). Do you think we should undertake an audit of cancer spending in NSW?

**STOP PRESS: The Baird Government has met the ALP's commitment to abolish chemo co-payments at NSW public hospitals, which brings NSW back into line with other states. A cancer consumer win!**

### Contacting NSW Cancer Services Directors

It is important for Cancer Voices to stay in touch with the cancer services around the state, so we – and they - can benefit from two-way exchange of issues, ideas and needs. We re-contacted all 14 Local Health District (LHD) Directors of Cancer Services on World Cancer Day – 4 February. Our purpose was to refresh existing relationships, and introduce Cancer Voices to those Cancer Services Directors who have recently taken on their busy roles. Some have got back in touch already with some enthusiasm.

### Calling NSW Cancer Centres

This year we plan to refresh our contact and our profile with all cancer centres in NSW, both public and private. The first challenge is to update the list, which is a priority project. Unfortunately the Cancer Institute NSW does not maintain a list like this, so we will develop it from the excellent website CanRefer. We may need some volunteers to help us sift through the information.

### IPTAAS – still on the agenda

Despite a most welcome increase in accommodation rates, the assistance offered by the IPTAAS (Isolated Patients Travel & Accommodation Scheme), and help with petrol only increased by 3 cents, and assistance to get to clinical trials was not addressed, once again. Cancer Voices wrote to the NSW Minister for Health to welcome her announcement this month, but to continue to flag the needs not yet addressed.

### Survivorship

The Survivorship Conference held in Adelaide in early February was well attended by Cancer Voices SA members who also made presentations, posters and chaired sessions. I gave the inaugural Ashleigh Moore Oration which was very well received. This is now on Cancer Voices websites and accessible on YouTube <https://www.youtube.com/watch?v=Ag6tSDuM3r4>

As a result of the conference, Cancer Voices has initiated a **Cancer Survivors' Framework for Survivorship Care** which will be put on our website after consultation with interested consumers. We will be working more closely with the various Survivorship Centres here in NSW and in other states (through Cancer Voices Australia) to get it out there.

### Lymphoedema Action

Cancer Voices has participated in meetings and planning by the Lymphoedema Action Alliance and formally become a member. We also supported a proposal to the NSW Government by Prof John Boyages (Macquarie University Cancer Institute) for funding for a Lymphoedema Education, Engagement and Expertise Program (LEEP).

### Access to Medical Cannabis

The NSW Government has developed criteria for the clinical trials for medical cannabis which were announced last year. Cancer Voices members have participated in proposals being put together by interested research groups. We are hoping that this process will be a quick and effective one.

Cancer Voices was invited to a special discussion meeting by the Department of Premier and Cabinet on 27 February and have accepted an invitation to comment on the Regulator of Medical Cannabis Bill 2014 currently before yet another Senate Inquiry.

Those with an interest in this issue should read a recent summary published in the Medical Journal of Australia: "Medical Cannabis: time for clear thinking – Australia is behind the times on the use of medical cannabis", at

<https://www.mja.com.au/journal/2015/202/2/medical-cannabis-time-clear-thinking>

Sadly Dan Haslam (25), who with his mother Lucy, had made such a difference to the thinking of NSW politicians, died of his cancer on 24 February.

The NSW Government has developed the **Terminal Illness Cannabis Scheme (TICS)** to extend compassion to adults with a terminal illness.

The scheme provides guidelines for NSW police officers to help them determine the appropriate circumstances in which to use their discretion not to charge adults with terminal illness who use cannabis and/or cannabis products to alleviate their symptoms and carers who assist them.

To register for the scheme, NSW adults (18 and over) with a terminal illness require a medical practitioner who is registered in Australia and involved in their ongoing care to certify that the person has a terminal illness as defined by the

scheme. Up to three carers may be registered for access under the scheme.

#### **Treatment & Care Plans – a Patient Portal**

We have looked into a product called *Equicare CS* which is an electronic treatment and care management software tool which interfaces with hospital/ clinic information systems to bring together all one's oncology data. This give a cancer patient and their treating clinicians a full treatment summary, long term-follow up plans, care team contact info and other useful informational material. In North America it gains COC accreditation for cancer care programs. We are checking on its use here.



## **Consumer Reps Programs**

Cancer Voices welcomes the Cancer Institute's NSW's call for interested consumers to join its new Consumer & Comment Advisory Panel. This is great news, there having been a noticeable hiatus on CINSW engagement with consumers over the last few years.

Check the Noticeboard and add your name to the CINSW Advisory Panel list – it's an opportunity not to be missed. Our members will be able to provide the informed, broad view to those CINSW projects with an impact for people affected by cancer.

This follows the January release of CINSW's Consumer & Community Engagement Framework.

### **Consumer Involvement in Research (CIR)**

The March quarter is the busiest of the year as cancer researchers finalise their grant applications. Over January and February, Cancer Voices CIR Manager, Bridget Whelan met many from researchers, introducing them to trained, and keen consumers on our CIR Database. All have undertaken the Cancer Council NSW / Cancer Voices NSW CIR Training course. We will advise members and readers of the dates for the 2015 training course in our June Newsletter.

Our proposal to record the CIR Program from the concept initiation in 2001 has been positively discussed with the Cancer Council NSW. We are all aware that if we don't publish an overview of how, why and with what results, it is hard to disseminate our learnings and experience to other consumer and cancer organisations which could benefit from our work to date.

Cancer Voices continues to advise the online CIR training module which is being led by the National Breast Cancer Foundation. Once this is launched, consumers interested in cancer research activities will be able to upskill or refresh their knowledge at any time.

We have also been invited to advise Health Consumers NSW on their own CIR training project.

The NHMRC is fine-tuning its portal to its generic website, built to make access to information about suitable clinical trials easy and fast. We were invited to provide input based on our experience of initiating and developing the Australian Cancer Clinical Trials website [www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au). Seeing a cancer project like this flourish into something which will benefit all health consumers is very rewarding.

### **THANKS!**

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

### Meetings

- Faculty of Radiation Oncology Council: 6 March
- NHMRC Clinical Trials website Portal: 12 Feb
- Cancer Australia – Review of Medicines and Medical Devices: 5 Feb
- PCHER – Operations Management Committee: 17 March
- NSW Dept. Premier & Cabinet: 27 Feb
- Cancer Council NSW: Consumer Involvement in Research: 18 Feb
- Cancer Voices NSW AGM: 11 Feb

### Conferences / Forums

FCIC Survivorship Conference, Adelaide: 6-8 Feb

### Submissions

Orphan Drugs Review  
Senate Inquiries: Availability of New, Innovative and Specialist Cancer drugs; Regulator of Medical Cannabis Bill 2014  
PBS Hospital Medication Charts

### Media

Dubbo: Daily Liberal, interview

*Oncology Network Newsletter:*

<http://oncologynews.com.au/surviving-is-not-enough-inaugural-ashleigh-moore-oration/>

YouTube

<https://www.youtube.com/watch?v=Ag6tSDuM3r4>

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## Cancer Voices Australia NEWS UPDATE

February 2015



cancer voices australia

### **Survivorship Conference 2015**

<http://www.survivorship2015.org>

Cancer Voices' Sally Crossing gave the inaugural Ashleigh Moore Memorial Oration on 6 Feb at the FCIC Survivorship Conference in Adelaide. This honours Cancer Voices SA's Founding Chair and his huge contribution to cancer consumer advocacy. The conference benefited from the strong input of SA representatives who assisted in the planning, chaired sessions gave presentations and posters. See links at

<http://www.cancervoicesa.org.au/awareness/community-noticeboard/2015-survivorship-conference>



### **Cancer Survivors' National Survivorship Framework:**

Consumers are now calling for a high level statement about best practice survivorship for people diagnosed with cancer and their carers. It should address what to expect and how to navigate through the post diagnosis cancer journey and beyond. The Framework will also help health professionals, including cancer specialists and allied health providers. This kind of guide is the basis for accreditation of cancer centres in some other western countries and is greatly needed here.

See Position Statement on CVA website, once consultation has been finalised (end Feb).

**Better access to cancer drugs:** Cancer Voices, ACCN groups and the CHF made submissions to the Senate Inquiry into *Availability of new, innovative and specialist cancer drugs in Australia*.

Cancer Voices submission is on our website. It and others will be viewable on [www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Cancer\\_Drugs](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Cancer_Drugs).

### **Gene Patent Appeal to be heard by High Court:**

This Appeal (mid-April) follows the 2014 Full Federal Court judgment that upheld the validity of the patent in relation to the BRCA1 gene associated with hereditary breast and ovarian cancer, contrary to

USA decisions.

**CVA contributions to current Reviews:** Review of Medicines and Medical Devices, PBS Medication Charts for Public and Private Hospitals Initiative; MSAC – IMRT & IGRT Agenda Items; Orphan Drugs Review; NHMRC Clinical Trials Portal; National Cancer Control Indicators; National Bill for Regulation of Medical Cannabis. The Sixth Community Pharmacy Agreement consult is due to commence soon.

**Consumer Involvement in Research:** Cancer Voices is participating in the development of Consumer Online Training for involvement in research with the NBCF and the Cancer Council NSW. We are also active in

the review of the NHMRC's portal to clinical trials. The CV "matching" service continues to link researchers with suitably skilled consumer reps.

### Consumers attending cancer conferences

Our call for a few registration free places to enable unsalaried cancer consumers to attend relevant conferences continues. So far this year, it seems this will only occur when we are invited to be Speakers. This is not adequate as our mutual goal with stakeholders is *real* consumer engagement. See Position Statement on CVA website.

### Recent Publications

ACCN's 'Who's Who' 2014 Directory – see <http://www.cancervoicesaustralia.org/accn/>. Now widely distributed, also available on request in electronic format via [info@cancervoices.org.au](mailto:info@cancervoices.org.au). As is a summary of the Australian cancer consumer movement's first 20 years which appeared in *Cancer Forum's* Nov. issue: [http://www.cancerforum.org.au//file/2014/November/13\\_Letter.pdf](http://www.cancerforum.org.au//file/2014/November/13_Letter.pdf)



2014 saw the twentieth anniversary of the Australian cancer consumer movement. To honour this, and Cancer Voices' role in its achievements, the journal *Cancer Forum* published my overview of those first twenty years – reprinted in our December Newsletter. The movement has a record to be proud of which is now recorded more formally. The year saw Cancer Voices NSW (CVN) strongly engaged in state and national level activities, the latter through Cancer Voices Australia (CVA) and the newly formed Australian Cancer Consumer Network (ACCN) – facilitated by CVA.

Cancer Voices has a new Patron: the Governor of NSW, HE General The Hon David Hurley AC DSC. The Hon John Fahey AO, previous NSW Premier and cancer survivor has, kindly agreed to continue his support as Vice Patron.

**Award for Excellence in Cancer Consumer Advocacy 2014:** Cancer Voices' annual Award for Excellence in Cancer Consumer Advocacy 2014 was made to Kathy Smith, at the Cancer Council's Research Awards presentation on 30 April and reported in the June Newsletter.

## ANNUAL REPORT 2014

**Advocacy issues:** Over 2014 we provided regular updates on the following advocacy issues identified by people affected by cancer, and our activities towards progressing them. These formed the basis of our NSW March 2015 Election "wish list", sent to the main political parties for response.

- Greater access to palliative care services
- Continuation & expansion of cancer nurse coordinator positions
- Legalising access to medical cannabis
- Access to high cost cancer drugs & security of supply
- Access to lymphoedema services and garments
- Cancer surgery waiting times in NSW Hospitals
- Consumers attending cancer conferences
- Best practice for coordination of cancer care
- Practice standards for medical oncology
- Co-payments for chemo in NSW public hospitals
- Up to date and comprehensive NSW cancer statistics.

### Working with stakeholders:

During the year, CVN nominees and the organisation itself worked with a wide range of "cancer world" stakeholders, at both state and national levels. These included

the Cancer Council NSW, Cancer Australia, the Faculty of Radiation Oncology RANZCR, the NSW Ministry of Health, the Cancer Institute NSW (in limited capacity), various NSW research institutions and cancer charities, National Health Performance Authority, Australian Commission for Safety & Quality in Health Care, the National Health & Medical Research Council, Consumers Health Forum of Australia, Health Consumers NSW, the Senate (Inquiries) and other advocacy groups.

### Consumer Representation and Training:

The main activity here was in the Consumer Involvement in Research Program, which has been reviewed, revived and extended. CVN continued to provide informed nominees to policy, service and support organisations as requested. Our website process facilitates this for all parties.

Three Consumer Advocacy Training (CAT) courses were held with CCNSW and their graduates invited to join Cancer Voices. Two Consumer Involvement in Research (CIR) training courses were held in September with the Cancer Council NSW. CVN advised on training programs for the Kolling Institute, Macquarie University Hospital, Kinghorn Cancer Centre and the Lowy (UNSW) Institutes.

## **Consumer Involvement in**

**Research (CIR) Program:** Under the management of Bridget Whelan, the CIR Program was fully restored, especially our free service for matching trained, informed consumers to the requests of researchers. We addressed the supply problem by reaching agreement with the Cancer Council NSW for two one-day training sessions for interested consumers. This was a huge success and CVN's database now holds a healthy bank of interested graduate registrants from which were made 54 "matches" during the year. Guides for consumers and researchers, clarifying their respective roles and responsibilities were developed and published. These have received very positive feedback by both parties and been extensively used beyond CVN's own CIR Program. They are available on the website.

**The Written Word:** Quarterly 8-12 page newsletters were published during 2014 and mailed in hard copy as well as being posted on the website for wider access. The December issue was our 57th Newsletter. They contain fuller details about Cancer Voices' 2014 activities and achievements. Major submissions were posted on the website, those related to national issues being accessible via the Cancer Voices Australia website.

**Speaking Out:** Members continued to attend many workshops, seminars, conferences and during 2014. This is a very effective way to contribute the consumer view about current issues, as well as enabling attendees to network and keep up to date and knowledgeable in the cancer arena. CVN published and promoted a

Position Statement about the benefits of sponsoring consumers to attend cancer conferences. CVN representatives continued to give invited addresses, and to contribute to related inquiries and to media debate.

**Electronic Communications:** CVN is gradually expanding our database of email addresses to be able to more quickly survey members of current issues. Our website is a home base for information about cancer consumer advocacy, consumer issues and representation. We also have a Facebook presence.

**Organisational :** 2014 saw a jump in new membership which we welcomed warmly, sending each a package of info and encouragement about finding a niche within our advocacy range. Group members total 80, and individual membership is 375. Newsletters are also sent to 117 non-members who want to be kept informed about CVN.

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.

**The 2014 Executive Committee** met every two months at the CBD offices of UBS Investment Bank (also pro bono), 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, Peter Brown, Roberta Higginson, Bridget Whelan, Jan Mumford, Brian Lemin, John Fullagar and Kathy Smith.

Members stepping up to make sure our fully volunteer organisation can operate efficiently

and communicate effectively make a big difference. We have been hugely helped by able and dedicated CVN members who responded to the calls for assistance: for database management, Sharon Pannewitz and for newsletter design, Kathryn Leaney. Our website was overseen by its designer, Kerryn Metcalfe and Facebook activity by Bridget Whelan. CVN, and I myself, very much appreciate this assistance.

**Financial:** The Treasurer's Report for 2014 is presented separately. CVN benefited from a welcome transfer of funds from member group BCAG NSW. The valuable volunteer work of members, of pro bono services such as newsletter printing and mailing by the Cancer Council NSW, kept expenses down.

**Recognition:** A big year of recognition, which indicates that the work we do with and for people affected by cancer, is externally appreciated. This was crowned by my receiving an Honorary Doctorate from the University of Sydney, as well as recognition in the AFR/Westpac 100 Most Influential Women list.

**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 for their interest in ensuring CVN's continuing success. Also thanks 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**

### **Contact CVN**

PO Box 5016 Greenwich NSW 2065: E: [info@cancervoices.org.au](mailto:info@cancervoices.org.au) W: Website [www.cancervoices.org.au](http://www.cancervoices.org.au)