

Message to Members

Your Executive Committee has settled into 2014, pursuing a number of issues affecting people with cancer in our state, which we report inside. Some of us have been very active within our national group, Cancer Voices Australia – as many national level issues, like access to cancer drugs, affect us all.

A big new consumer voice

A new independent network called the Australian Cancer Consumer Network was established on 1 April - currently made up of 27 groups. It is facilitated by Cancer Voices Australia. We feel confident that this will give cancer consumers an even clearer and more respected voice on national issues, submissions and advocacy.

Award for Excellence in Cancer Consumer Advocacy

The big excitement this quarter was the announcement of this year's Cancer Voices NSW annual *Award for Excellence in Cancer Consumer Advocacy* on 30 April. Kathy Smith is our deserving recipient – more inside about Kathy's story – one which exemplifies the successful route from local to national level advocacy.

Consumer Involvement in Research

We have been working with the Cancer Council NSW to add a new component to this year's Research training to better equip the consumers we nominate to work with cancer researchers. Cancer Voices has also developed two advisory leaflets to guide our consumers and the researchers they work with – we think this improvement which will help all parties.

Thanks to our own volunteers

We were delighted by your response to call for help with some essential admin tasks. We now have a very competent manager of our databases and – as you can see – a major formatting upgrade for this newsletter.

One of Cancer Voices strengths is its independence. We rely on neither government or industry funding to underpin this. It means our success is underwritten by our members who can help us operate effectively as well as those who take on representative work on decision-making committees and with researchers. So, a big thank you to all those who give their time, interest and expertise towards supporting an informed, independent cancer consumer voice in NSW!

Sally Crossing AM Chair

Special points of interest:

- * Advocacy Training in 2014 — Page 2
- * Consumer Involvement in Research Training in 2014 — Page 2
- * Cancer Voices NSW Award for Excellence in Consumer Advocacy — Page 3 & 8

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Presentation of Cancer Voices 2014 Award to Kathy Smith for Excellence in Cancer Consumer Advocacy at the Cancer Council NSW's Research Awards event, 30 April 2014

(See Page 8 for Sally Crossing's Speech)



CVN Notice Board



Consumer Advocacy Training (CAT) Courses 2014

5/6 September – Sydney

14/15 November – Central Coast (date to be confirmed)

Cancer Voices partners with Cancer Council NSW to run a two-day Advocacy Training Workshop for CVN members, community members, and people with cancer (families and carers).

This two-day workshop will help you speak up about issues affecting people with cancer and to learn how to be an effective consumer representative.

The 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 TRAINING 2014

– 5 & 6 September

Please note slight date change!

This annual introduction to becoming a consumer advisor to cancer researchers will be held again in September.

We encourage anyone interested in the direction and methods of cancer research, from epidemiology, “bench top” biology, treatments and psychosocial research, to consider signing up to the course.

Cancer researchers need your consumer perspective!

The 2014 training has a new segment to especially equip Consumer Research Advisors. “Graduates” can join our “match-making” database, through which we can offer you research projects where your advice will be highly valued. They will also be considered for the Cancer Council’s Consumer Review Panel.

For Expressions of Interest forms visit
www.cancercouncil.com.au/research/research-profile
Phone: (02) 9334 1445, Email: samth@nswcc.org.au



DONATION TIME

**Donations to Cancer Voices are
tax deductible**

If you would like to support the work of Cancer Voices, please send donations to PO Box 5106, Greenwich 2065, with your name and address.

Donor contributions are used to cover expenses incurred by our volunteers when on CVN advocacy business, and for postal and printing costs.

To ensure our independence we do not seek grants from government or industry.

Cancer Voices will mail a receipt for your tax return ASAP.

THANKS!

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

Cancer Voices NSW Executive Committee met on 9 April and our next meeting is 18 June. As usual, most advocacy occurred between meetings. Our 2014 team is active and engaged, apart from a few well deserved absences overseas!

Thanks to new CVN helpers

Big thanks to those who kindly responded to last newsletter's request for help with a range of essential tasks – we now have helpers for maintaining CVN's main database, for running our Consumer Involvement in Research "matching" Program and – as you will see this issue – for formatting our masthead newsletter. Our heartfelt thanks to all!

Meeting with Cancer Council

Five CVN Executive Committee members met with the CEO, Jim L'Estrange, and senior Directors of Cancer Council NSW on 6 May. This is a valued six-monthly exchange of key interests and identification of where we can collaborate best in the interests of people affected by cancer.

This award was announced on 30 April at the Cancer Council NSW's Research Awards presentation. This was a particularly memorable event, hosted perfectly by Adam Spencer.

The 2014 recipient is Kathy Smith – for her outstanding advocacy work at local, state and national levels. Not only has Kathy made a substantial contribution as a very active cancer consumer advocate, but her story offers an excellent example to others about how 'big things from little things grow'

See page 8 for Chair, Sally Crossing's speech on the night.

Congratulations Kathy.



The Voices being heard

A quieter quarter, other than those major meetings and events already reported upon. Regular committee meetings for our reps continue apace.

Media: CVN provided advice and contacts to SBS Insight program aired on Cancer, 6 May

Cancer Voices Website

Our smart new website is working well.

This month we have uploaded some new or updated Position Statements, which you may wish to check. Their format has been improved as well.

- ◆ Consumer Representation
- ◆ Consumers at Conferences
- ◆ Radiotherapy
- ◆ Coordination of Care
- ◆ Relationships with Pharma
- ◆ Consumer Involvement in Research

www.cancervoices.org.au



Contact CVN

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Coordination of Care

Cancer Voices continues to press for a set of guidelines or similar to assist both clinicians and patients, offering best practice pathways in the coordination of care for cancer patients. We believe that if we cancer patients and our carers knew what to expect from whom, and where to turn for help when needed, our experiences would be very much better. In May we discussed options for achieving this with senior people at Cancer Australia, the aim being to bring together those agencies and groups with a demonstrated interest in addressing the current gaps in practice. These will include COSA's Cancer Care Coordination Group and the Cancer Institute NSW.

Interest shown so far is very encouraging – we hope to bring firmer good news in our next newsletter.

Consumers attending cancer related conferences

Following last newsletter's discussion about the ability for cancer consumers to benefit by attending conferences, Cancer Voices has developed a Position Statement on this issue (see CVN website).

This forms the basis of our approach to potential funding bodies, who we believe should be interested in assisting consumers to keep up to date, have networking opportunities and improve their ability to contribute to discussion and decision making.

Cancer Voices Australia has raised this with the Clinical Oncology Society of Australia (COSA), whose major cancer conference takes place in early December. We are also considering other options for third party support, possibly through industry associations or the like.

Medical Cannabis – some progress Drug Legislation Amendment (Use of Cannabis for Medical Purposes) Bill 2014

Earlier this year Dr John Kaye MLC (Greens) gave notice of a Bill relating to the legalisation of medicinal cannabis in the Legislative Council in the NSW Parliament. The Bill implements Recommendation 2 of the unanimous findings of the cross-party Upper House Inquiry conducted last year into the use of cannabis for medical purposes.

Cancer Voices contributed to discussion and the hearings. It makes it lawful for patients with a terminal illness (or another illness as prescribed by the regulations) to possess and consume cannabis to relieve some of their pain and discomfort, as well as making it lawful for their carers to supply it to them. Only patients and carers listed on a NSW Health register may be exempt from prosecution.

The Bill was launched in NSW Parliament House on Tuesday 27 May and Cancer Voices was invited to attend.

Invited speakers were from across the political spectrum, affected patients and experts in the field. While the Greens had preferred the Bill to be much broader in its scope, they decided to limit it to the unanimous finding of the cross-party Legislative Council Committee. The NSW Government had previously rejected the Inquiry's recommendations.

Dr Kaye says "Our bill is really not controversial. The NSW government is letting this state fall behind the rest of the world by denying dying patients and their carers an avenue to make their lives slightly better". See more at : <http://johnkaye.org.au/campaigns/support-the-greens-bill-to-legalise-medicinal-cannabis/>

Cancer Voices has asked the NSW Government for a copy of the Commonwealth's response to the Legislative Council's recommendation that the two governments explore options. We are also asking that conscience voting be allowed by the Coalition to better reflect community views. More American states have legalised access, accepting evidence that no harm is caused by allowing carefully controlled medical use of cannabis for symptom relief. Why not in NSW?

Clinical Practice Standards, please

Cancer Voices – NSW and Australia – continue to seek the adoption of Practice Standards for Radiation Oncology (which are well developed and available) and for Medical Oncology (yet to be developed) by state Government. We understand those for Radiation Oncology are under consideration by the NSW Ministry of Health.

On the advice of the Medical Oncology Group of Australia, Cancer Voices has formally approached the Royal Australian College of Physicians (RACP) about developing a set of Practice Guidelines for Medical Oncology.

Access to High Cost Cancer Drugs

Cancer Voices took part in the Stakeholder Forum, 26- 27 March, in Canberra by the by the Cancer Drugs Alliance (CDA), a combined group of pharma companies, clinicians and consumers. We have agreed to work closely on the resulting committees to ensure the independent consumer view is included. Richard Vines of Rare Cancers Australia, and a Cancer Voices friend, is the consumer contact and media spokesperson for CDA.

The big new voice - ACCN

The CDA Forum created a first of its kind opportunity for cancer consumer groups to meet each other. Realising how much stronger our voices would be, an independent network of the 18 which met in Canberra has been expanded to 27 cancer consumer groups – under the banner **Australian Cancer Consumer Network**. This is currently facilitated through Cancer Voices Australia.

A home for Cancer Guidelines

CVN and CVA are advocating for a central repository of all published guidelines for cancer treatment and care. These are presently scattered about the sites of the organisations and agencies which have developed them, with a rather obscure portal, just discovered within the National Health & Medical Research Council.

Ideally we would like to see them easily accessible via Cancer Australia's website – as this is where patients, other consumers, clinicians, researchers, nurses and GPs would normally turn for them. The overseas collations are interesting in comparison – try ASCO in the US and NICE in the UK.

Lymphoedema advocacy

Roberta Higginson (Chair BCAG NSW and CVN Executive Committee member) is our representative on the meetings of the new Lymphoedema Action Alliance which met on 21 May. Its aim is to improve the journey for people with lymphoedema.

The Cancer Council NSW has been working with a wide range of organisations including the Australasian Lymphology Association, Lymphoedema Support Group of NSW, YWCA Encore, CWA, BCNA, Melanoma Inst Australia, Ovarian Cancer Australia, Breast Cancer Action Group NSW and Cancer Voices NSW to identify issues and explore ways of working in a collaborative lymphoedema advocacy campaign.

A working party has been formed for each of the issues below:

1. To improve access to lymphoedema services in NSW
2. To include compression garments on the Medical Benefits Scheme

Cancer Voices is contributing to both.

Public cancer treatment at Chris O'Brien Lifehouse

"Chris O'Brien Lifehouse - the new, state-of-the art cancer treatment and research facility, providing integrated care to patients and support for carers and their families - has now been open for six months. As a not-for-profit public benevolent institution, Lifehouse provides patient care and treatment through a number of clinics for both public and private cancer patients.

Lifehouse combines all aspects of clinical treatment, information, research, complementary therapies and emotional support. Everything a patient needs is available in one place alongside clinical treatments including allied health, complementary therapies and psycho-social support.

To find out more about our model of care and range of patient services, please visit the Lifehouse website at www.mylifehouse.org.au or call 1300 852 500 to speak with a member of the Lifehouse team."

Following some member queries about options for public cancer patients at Lifehouse, Cancer Voices has been advised they remain the same as when offered by Sydney Cancer Centre at RPA, except that expanded services (other than clinical) attracting a fee are available.



Lymphoedema Action Alliance meeting at the Cancer Council NSW, 21 May 2014

Consumer Involvement in Research

Cancer Voices matching service

Cancer Voices CIR Program has been recharged under new management by Bridget Whelan. We have also spent time to address the needs of those we nominate through our matching service, and indeed requesting researchers themselves.

Over four months this year we have made 22 placements covering issues like children's' tumours, head and neck, skin, pancreatic, breast, prostate, gynae, colorectal and brain cancers as well as issues such as radiotherapy services and effects of cancer treatment. We placed people with researchers at the Garvan, Chris O'Brien Lifehouse, UWS, University of Wollongong, University of Sydney, University of New South Wales and the Centenary Institute at RPAH. Many other nominated consumers continue to work with their matched researchers as projects are funded and developed.

Breast Cancer Special Interest Group (Univ of Sydney Cancer Research Network).

Cancer Voices members have been invited to speak about the role of consumers in the research process in 2013 and 2014.

This year, Sally Crossing gave the opening address to about 100 attendees, on 12 March.



New CIR training component for 2014

Discussions with the Cancer Council NSW took place in May towards development of a new segment in the annual training program. As well, Cancer Voices has developed Advisory Sheets to assist both the consumers we nominate and the researchers they will work with. The aim is to clarify expectations about roles, making the engagement as productive and positive as possible.

We encourage any members with an interest in cancer research, who have not undertaken the Consumer Involvement in Research Training, to do so in 2014. It will be held in Sydney in early September – see Notice-

board (p2) for more details and on our website. It's a great way to contribute the consumer view to cancer research AND we really do need more trained consumers to help researchers this way!

Consumer Reps Program

Cancer Voices will continue to provide nominees to **Consumer Advocacy Training** courses – for 2014 new dates, please see Noticeboard on page 2.

Cancer Voices continues to provide nominees who are graduates of these two-day courses to policy and decision making organisations which request, as received via our website request forms. Graduate are most welcome to contact us on advocacy issues more generally.

Role of Consumer Representatives

An updated Position Statement, posted on CVN's website clarifies the principles upon which we operate in relation to consumer representatives – nominated CVN members who provide the broad, informed consumer view.



WHAT'S HAPPENING AT STATE LEVEL

Cancer Council NSW

We very much appreciate the moral and practical support extended to us by the Cancer Council NSW, especially in those areas where our interests are mutual – which are many! Below is a brief summary of current CCNSW activities which we think will be of interest to you.

"Cancer Council NSW is the only organisation that works across every area of cancer; conducting and funding world-class research that underpins our work in preventing cancer; advocating to ensure that governments take action on cancer; and supporting people as they navigate the cancer journey.

One of its priorities is to empower and support people affected by cancer, so that no one need face cancer alone. They do this by providing information about cancer, and practical and emotional support.

Cancer Council NSW provides up-to-date, evidence-based information for people who have questions about any aspect of cancer, including diagnosis, treatment and where to turn for help. They provide a confidential telephone service where people can speak to a specialist cancer professional about anything to do with cancer and last year alone they received over 18,000 calls.

For people with cancer, talking to someone who has been through a similar experience can be helpful, reassuring and encouraging and Cancer Council NSW offers a range of ways for people affected by cancer to connect on-line, in person and on the phone.

Some people affected by cancer need assistance with the practical day-to-

day issues that can arise following a diagnosis or during treatment which can impact other areas of their life. Cancer Council NSW offers a range of practical support which, depending on where you live, could include assistance with transport to treatment, accommodation, and in-home help. They also offer legal and financial planning assistance, new workplace and small business advisory services.

This is just a small sample of the support that Cancer Council NSW is able to offer anyone affected by cancer. There is also a comprehensive range of information and resources on the website. Contact them to find out more on 13 11 20 or www.cancerCouncil.com.au.

Cancer Institute NSW Cancer Institute's Consumer Engagement Strategy

A few of us were invited to a presentation about this on 26 May. Unfortunately the CINSW Strategy has been developed without consultation with the people with whom it intends to engage. We find this an unusual approach by a government agency, or indeed any other body interested in consumer engagement.

Cancer Voices Chair, Sally Crossing, will meet soon with CINSW CEO, Prof David Currow to discuss issues, for people affected by cancer in NSW, and how we can more productively work together - as the peak generic cancer consumer organisation and the state's principal cancer agency.



WHAT'S HAPPENING NATIONALLY

Budget 2014

Cancer Voices welcomed the document of a Medical Research Future Fund (MRFF) due 1 Jan 2015, with an aim to receive a target capital of \$20billion from 2015 to 2020. It will be important that cancer research is made a priority.

We were also very pleased to hear that the long awaited Bowel Screening Program has been committed to.

CVA was invited to a Budget Briefing by the Department of Health on 13 May. Susan Pitt represented CVA at the 'lock-up' and reported back.

Medicines Australia's Code of Conduct Consultation

Cancer Voices NSW attended the Medicines Australia forum on the proposed changes to their Code of Conduct. The Code regulates the behaviour of most of the prescription pharmaceutical drugs industry.

The key changes were to introduce transparency around the gifts and sponsorship pharma companies provide to doctors etc.

Unfortunately after reviewing the proposal, CVN considers it inadequate for a number of reasons:

- * it relies on each doctor consenting to the information being made public;
- * there is up to a ten month delay in the gift etc being given and the information being available to patients;
- * the information will only be provided where a gift is given to an individual doctor, and not where, eg, when it is given to a doctor's practice;
- * the information will only be available separately on each drug company's website, not on a central searchable database.

The upshot of the current proposal is that, from a patient's perspective, we will be able to see that our doctor has directly received (ie not through their practice etc) a benefit from a pharmaceutical company regarding the new drug she/he put you on, if your doctor consents to it being made public, about 10 months later.

Cancer Voices has written to Medicines Australia making clear our concerns and disappointment.

There will be an opportunity for public comment when the ACCC considers approving the new Code in the second half of this year.

Cancer Voices will be making a submission to that process which outlines the reasons why we think the proposal is almost useless in providing transparency. When the details are available, we will put them on our website so any members who wish to make a submission can do so.



CANCER VOICES NSW AWARD for Excellence in Cancer Consumer Advocacy

(Address by Sally Crossing AM, Chair, Cancer Voices NSW, 30 April 2014)

Thank you Cancer Council for including Cancer Voices in your annual Research Awards presentation event... and for being such a good and responsive partner. We have worked closely together over the last ten years to develop Australia's leading program for meaningful consumer involvement in research.

Before announcing this year's recipient of our own AWARD for Excellence in Cancer Consumer Advocacy, I'd like to offer you reassurance about our free and volunteer "match-making" service, matching informed consumers to researchers seeking their input. It is right back on track and connecting successfully, as many of you will know. We had a short service wobble caused by a 300% increase in requests for consumer advisors in 2013!

As part of Cancer Voices' Consumer Involvement in Research Program, I'd also like to tell you about, and launch a new aid for the consumers we nominate to provide their informed perspective to you and your projects and grant applications. It's an advisory sheet which is very clear about the role of a consumer nominated by Cancer Voices when working with researchers. There has been a demand for this by those nominees, and we have met it. As the Program matures, expectations of all parties need to be very clear. The next step is to work up something similar for researchers themselves.



Tony Maxwell (CVN), Sally Crossing (CVN), Adam Spencer, Amy Marshall, Sam Thorpe (CCNSW) and Kathy Smith (CVN) - superimposed!

AWARD for Excellence in Cancer Consumer Advocacy 2014

Cancer Voices is proud to announce that Kathy Smith is our 2014 Award recipient, the third bestowed.

Kathy Smith, a breast and mouth cancer survivor has made an outstanding contribution to cancer consumer advocacy. Over the last seven years she has worked extremely effectively at local, state and national levels to improve the experience of people affected by cancer. As a valued consumer representative, she has also contributed to many major decision-making committees, in relation to policy, service delivery, information access and research. A brief description of her activities will give you a good idea as to what good best practice consumer advocacy is all about.

Local Action

Kathy spearheaded a campaign on the Central Coast calling for public radiotherapy facilities for the local community of 312,000 residents. This was hard fought - involving lobbying and petitioning of many politicians at local and state government level, from local Members to Ministers and Premiers. She eventually took the issue, a state government responsibility, to the federal government level by organising a further petition and meeting with federal Members and Ministers. Through

electronic and print media, public addresses and petitioning, Kathy raised the interest and support of the Central Coast community who, once aware of the plight of local cancer patients, were more than keen to support Kathy's work. The campaign culminated in Kevin Rudd, then Prime Minister, visiting the Central Coast in April 2010 to announce funding for a Regional Cancer Centre, which of course incorporates the public radiotherapy facilities. Kathy worked with the planners to ensure the new centre would be fully patient friendly and that transport for out of area treatment was provided. The Central Coast Comprehensive Cancer Centre was opened on time on 2013 by Prime Minister Julia Gillard, with special mention of the Kathy's role.

State level advocacy leadership

Kathy joined Cancer Voices at the start of her central coast advocacy and quickly became a fully engaged and contributing member. She served as Deputy Chair from 2009 – 2011, then as Chair until this year. Kathy provided policy and advocacy advice on all major issues arising at state level and acted as media spokesperson. In 2011, Kathy took on responsibility for database management – and steered the growing match-making of consumers with researchers' requests.

National level advocacy contribution

At the national level of cancer consumer advocacy, Kathy served as Cancer Voices NSW's nominee to Cancer Voices Australia (CVA), representing CVN on its Management Committee. Kathy is now a member of CVA's Executive Committee, which is ably steering the national level voice for people affected by cancer on issues overseen by the federal government, its cancer related agencies and professional colleges.

Reflection: Kathy's highly effective career as a cancer consumer advocate perfectly demonstrates how the trajectory works best. With the necessary ingredients of commitment, passion and understanding, success at a local level leads onto the wider area and bigger issues for more people affected by cancer.

Bonding with Cancer Voices, the recognised voice of those people, provides the platform and back-up.

Cancer Voices believes Kathy is a most worthy recipient of the 2014 AWARD for Excellence in Cancer Consumer Advocacy.

Unfortunately Kathy Smith is unable to be here in person, but she has asked me to thank not only Cancer Voices, but the Cancer Council NSW, our host and partner, and NSW's excellent cancer researchers – with many of whom she's had productive engagement. Congratulations Kathy!



Access to cancer drugs

Cancer Voices and 16 cancer consumer groups and other organisations which advocate for people affected by cancer, took part in a two-day Stakeholder Forum in Canberra, 26 & 27 March. Hosted by the Cancer Drugs Alliance (CDA), the gathering of clinicians, industry, government and consumers, examined ways to ensure our HTA approvals processes, especially those for PBS subsidised drugs, better reflect both the specific characteristics of cancer drug development and those of cancer patients.

www.cancerdrugsalliance.org.au

Guidelines for coordination of cancer care

Our efforts towards recognition of the need for best practice guidelines for coordination of cancer care, throughout the cancer journey, but especially at end of life, are gaining traction at last. CVA is to meet with Cancer Australia (CA) senior staff in May to discuss options, noting the outcomes of the recent CO-SA and Cancer Institute NSW conferences on the topic.

Establishment of Australian Cancer Consumer Network (ACCN).

Building on the framework of CVA's own cancer consumer network established last year, a wider national level cancer consumer network has been facilitated through CVA. The impetus for this was the opportunity to meet face to face at CDA's Stakeholder Forum, where the need for an independent consumer collaboration to provide *a more effective consumer voice on national issues* was clearly recognised. While access to drugs is a first priority, the new network (27 participant groups to date) will be able to address other important issues, support each other and share information. A catchier name may be found!

Chemotherapy Funding Review

All welcomed the Government's interim \$82m package which covers the situation until 1 July 2015. We

understand that future funding will come under the next Community Pharmacy Agreement (6CPA). CVA joins other stakeholders in calling for the parties to the upcoming 2014 6CPA negotiations to be broadened beyond Government and the Pharmacy Guild of Australia, the pharmacists' union, to include community interests.

Security of cancer drug supply

This continues to concern us on two counts: (i) when pharma decide not to continue supplying a drug already on the PBS, and (ii) when they discontinue Special Access support due to failure to get PBAC approval for a drug. Both can leave patients and their clinicians in difficult and distressing situations.

CVA submissions on Health Technology Assessments, Guidelines and Inquiries

CVA has made several submissions, sometimes in support of network members, on several HTA agenda items – both for PBAC and MSAC. We also provided comment on two Cancer Australia Draft Guidelines and Government Skin Cancer and Out of Pocket Costs Inquiries.

CVA welcomes the new Parliamentary Friends Cancer Group.

Co-Chair, Sen. Deb O'Neill has welcomed our regular raising of issues of interest and concern for Australians affected by cancer. Dan Tehan MP from Victoria is Co-Chair and opened the CDA Stakeholder Forum.

Vale Ashleigh Moore OAM

Cancer Voices deeply misses one of its leading lights, Ashleigh Moore, who died on 3 Feb. Ashleigh was Chair of Cancer Voices SA and contributed greatly to numerous national committees. See a tribute to him at www.cancervoicessa.org.au/awareness/community-noticeboard/ashleigh-moore-oam-rest-in-peace

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

[Editor]: Cancer Voices Australia NEWS UPDATES are issued every two months, the next being June.

If you would like to receive them directly by email, please request via info@cancervoicesaustralia.org and we will add you to the email list.

You are also most welcome to join CVA, via the website www.cancervoicesaustralia.org



We can all help find the answers to cancer

Register4 brings together researchers and people who share one common goal – to help deliver greater health benefits from cancer research, faster.

In Australia, it is estimated that 1 in 2 men and 1 in 3 women will be diagnosed with cancer by the age of 85.

The big “C word” is so prevalent that it has almost become part of our everyday vocabulary, leaving many of us feeling helpless and as though we’re swimming upstream. Research holds the key to improving survival rates and improving the quality of life for people with cancer, their family and friends.

What if you held some of the answers to questions about cancer? Whether you are an individual interested in participating in cancer research or a researcher wanting to fast-track cancer research, with Register4 we can all help researchers find the answers to cancer.

One of the biggest challenges for researchers is finding the right people to participate in their cancer research. Researchers can sometimes spend up to two years to recruit participants for their projects delaying the actual research.

Register4 is an online community that brings everyday Australians interested in participating in cancer research together with cancer researchers to fast-track their research.

Register4 is an initiative of the National Breast Cancer Foundation. Established in 2010, it aims to reduce the cost and time involved in recruitment process for cancer research studies.

By introducing researchers with willing and suitable participants – harnessing the speed and reach of the internet – Register4 is able to fast-track the recruitment process to just two days in some cases.

Each and every one of us can help cancer research – and Register4 is just one way the community can contribute.

Getting involved with Register4 is simple. It only takes 3 minutes to join and it’s absolutely free. It’s strictly confidential and anyone aged 18 years or over with or without cancer can take part.

Participants are invited to register on-line at www.register4.org.au where you will be asked to provide some basic information.

Once you’ve signed up, Register 4 will ask if you are interested in participating in scientifically-appropriate and ethically-approved research studies. The types of projects can vary from filling out a questionnaire to something more involved such as providing a DNA sample. It is always your choice to participate in research projects.

Please join Register4 at www.register4.org.au - remember you could hold the key to a cancer breakthrough.

Further information can be found on the website: <https://www.register4.org.au/> via email: info@register4.org.au or telephone: 1300 709 485.

Contact CVN – The voice for people affected by cancer

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW, to improve the cancer experience of the over 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care.

To achieve this, we work in partnership with decision makers and providers of these services, ensuring the patient perspective is heard from planning to delivery.

PO Box 5016 Greenwich NSW 2065:

E: info@cancervoices.org.au

W: Website www.cancervoices.org.au

