

Message to Members

This edition of the CVN Newsletter reaches a notable milestone. It's the **FIFTIETH EDITION!** Hard to believe for those members who have been around to read them all and to consider the information conveyed in them, as well as news of all the successes achieved in that time. It could not and would not have been possible without the support and input of our members. Something to be proud of, indeed.

February saw **Rare Cancers Australia** become a member of CVN, and we welcome them and their work to our membership. Richard and Kate Vines started this group in mid-2012 to gain recognition and action for the 200 or so cancers that fall outside the net that catches the more commonly known, or commonly occurring cancers. *See page 6 for more information on this welcome addition to cancer consumer advocacy.*

February also saw the launch of the **National Indigenous Cancer Network (NICaN)** in Sydney. This is a national network that encourages and supports collaboration around indigenous cancer research, and delivery of services to Indigenous people with cancer, including carers and families. *See page 9 for more information.* Since the launch of NICaN, I have received, and have been pleased to accept, an invitation to join the Advisory Board for Australia's first Centre for Research Excellence in Cancer and Indigenous People : **Discovering Indigenous Strategies to Improve Cancer Outcomes via Engagement, Research Translation and Training (DISCOVER-TT).**

SAY NO TO GENE PATENTS. As I am sure all members will be aware, on Friday, 15 February, 2013 the Federal Court handed down a negative decision regarding the ability to patent BRCA1, a breast cancer gene mutation. Maurice Blackburn Lawyers, Cancer Voices Australia, and Ms Yvonne Darcy brought this challenge against the patenting of human genetic material on the basis that genes are not an invention to possess and patent, but were naturally occurring in nature.

Community distress at this decision has been very evident, with a number of eminent people expressing their concerns. In the opinion of Professor Ian Frazer, previous Australian of the Year, "there is no more invention in isolating and characterising isolated biological materials that exist in our human bodies ... than in collecting and arranging a set of postage stamps." Professor Frazer has called on the Australian Parliament to amend Australian patent law to "exclude gene sequences from the definition of patentable subject matter". It would seem, in light of the decision of Justice Nicholas, that our politicians must now answer his call. And we believe it is critical that they do so.

Join Cancer Voices' Petition which calls for an amendment to clearly exclude the ability to grant patents over human genetic material. Sign the electronic petition at: <http://www.change.org/en-AU/petitions/change-the-law-to-stop-patents-over-human-genetic-material>, and copy the insert with this newsletter.

On that note, I wish all a belated successful and healthy 2013 and leave you to continue reading your Newsletter.

Kathy Smith, Chair



Cancer Voices NSW – Executive Committee 2013
(Bridget Whelan – not present)

NO TO PATENTS ON HUMAN GENES CAMPAIGN

Join us to stop biotech companies owning our genes!

See the insert in this newsletter for the things you can do to help fix this extraordinary situation
Cancer Voices is calling for an amendment to the Patents Act 1990
to remove the ability to put patents on our genetic material

Decision-makers need to hear from lots of Voices!

Our campaign will use a Petition to Parliament, social media, interviews, letters to Ministers and MPs...First
sign up at

<http://www.change.org/en-AU/petitions/change-the-law-to-stop-patents-over-human-genetic-material>

Then print copies of the Petition Sheet for Parliament and fill with signatures and mail!

CHEMO COSTS WATCH

Have you been charged more than once, or more than the standard co-payment
for any cancer-related drug, during treatment at public or private hospitals, as an outpatient?

Let Cancer Voices know ASAP

This information will be most valuable for our discussions with the NSW Ministry of Health

See Cancer Voices contact details on page 11

We need to hear from you about

Cancer treatment in private hospitals & clinics – your experiences?

Cancer Voices is seeking stories of experiences – good and bad
of cancer treatment in the private sector in NSW.

These will help us shape & demonstrate the issues supporting advocacy for best clinical practice to be adhered
to. Send to CVN by 12 April - Names will be withheld if requested.

Excellence in Cancer Consumer Advocacy Award 2013

Nominations (last call- we have one so far) are sought for this Award, now in its second year
to **info@cancervoices.org.au** or to **PO Box 5016, Greenwich 2065** by 28 March
Presentation to be made at the Cancer Council Research Awards night in late April/early May.

Consumer Advocacy Training (CAT) Courses – 19 & 20 July 2013

To help you speak up about issues affecting people with cancer.

Would you like to be more effective in your advocacy and committee work?

CVN partners with Cancer Council NSW to run a 2 day Advocacy Training Workshop for CVN members, community
members, and people with cancer (families and carers)

The workshop provides skills and tools to improve confidence to make a difference, and will equip you to :

- Become active and effective advocates for better government cancer policies and services
 - Approach your consumer representative work more confidently
- Understand how government works, and how you can influence decision-makers

To apply and to check venues, please refer to : **<<http://www.cancercouncil.com.au/advocates/workshops>>**
or contact **Cancer Council NSW (Policy & Advocacy) on (02) 9334 1406** or
advocacy@nswcc.org.au to request an application form by post

CVN Executive Committee Business

Your Committee met on 17 October and 13 December 2102. Next is 13 March.

Annual General Meeting

Cancer Voices NSW's Annual General Meeting was held on 6 February, followed by a short meeting for the 2013 Executive Committee.

Committee and Office Bearers for 2013 are:

Chair : Kathy Smith
Deputy Chair : Sally Crossing
Secretary : Sally Crossing
Treasurer (co-opted) : Sandra O'Sullivan
Committee Members : Roberta Higginson, Bev Noble, Tony Maxwell, Elisabeth Kochman, Peter Brown, Kate Vines, and Bridget Whelan

Kathy Smith presented her Annual Report for 2012, which is reprinted in this Newsletter. The 2012 Financial Statements were tabled, and thanks conveyed to our Treasurer for preparing them.

New Executive Committee members, Bridget Whelan and Kate Vines, were especially welcomed to help us during 2013. Between them, they bring experience of rare (see page 6) and gynaecological cancers.

Member Data as at 1 March 2013

- Voting Member Groups = 74
- Individual Members = 312
- Organisation Members = 12

 **CONSUMER REPS IN ACTION**

Nothing about us without us!

This year we are taking stock of the strategies in place, or being developed, around regular and consistent consumer engagement by the principal cancer stakeholders. These include organisations like the Cancer Council NSW, the Cancer Institute NSW, other research funding bodies, and any organisation whose work can impact on the cancer experience. CVN would like to see agreement and adoption of Best Practice Principles for Consumer Engagement across the board. In some organisations this is firmly entrenched, but others may waver and change when new staff move in. Always a challenge, but short formal agreements seem to be the way to go.

Overall Consumer Representation

We service a total of 187 committees of different types. 80 nominated individual consumers sit on these committees for 57 different organisations. (This does not include the reviewing activities for cancer organisations and agencies).

Consumers advising Research Projects

There are 95 individual research projects within 24 organisations for which CVN provides consumer input.

 **CVN ADVOCACY UPDATES**

This quarter's advocacy focus has been on the following issues :

Private Cancer Treatment

Cancer Voices' members have reported problems related to the standard of treatment and support in some private cancer clinics and hospitals. All NSW hospitals must meet accreditation standards, but these do not apply to clinical treatment standards.

Cancer Voices would like to hear about your experiences in the private sector - costs, standard of treatment and care, access to information and support for decision making, etc.

Your own stories are very valuable to us. We can assess the range of problems, their degree of difficulty for people affected by cancer, and refer to decision-makers about how to improve those experiences in the future. *See Noticeboard invitation page 2.*

Cancer Voices are looking into advocating for reassurance that cancer treatment and care in the private sector are in line with the Best Practice Guidelines and protocols used by the public system. We understand that 60% of cancer patients are treated in the private sector.

CVN has brought this issue to the attention of the Cancer Council NSW, which is also interested in this area, and we will work closely with them.

Palliative Care Campaign

Better Palliative Care in NSW

Tenders for palliative care projects across NSW have closed. CVN was asked to support two of these. These are to be funded by the \$35m over four years augmentation package announced by the Minister of Health last October. We will be watching the outcome with interest.

Palliative Care Alliance: Cancer Voices has invited other health consumer organisations whose members may need palliative care, to form a Palliative Care Alliance. This will increase the strength of our voice well beyond cancer, which apparently accounts for about 70% of palliative care.

Increase the funding: Cancer Voices continues to recommend to government that funding should be brought up to at least Victorian per capita standards and allocated on a need basis across the state. Yvonne McMaster continues her rural NSW travels and keeps us up to date about areas which are particularly needy.

PCEAG Report: A 19 November request by CVN for the release of the Palliative Care Expert Advisory Group's report completed last year, following the Minister's commitment to review and improve NSW palliative care services, has been denied - almost three months later. We are considering a Freedom of Information application.

Chemo Co-payments

The Ministry of Health has issued a Policy Directive which came into effect on 1 January which states "Chemotherapy patients pay only one co-payment for each original prescription dispensed for chemotherapy medicines for injection/infusion, but **not** for repeat prescriptions". This should ensure that cancer patients are not charged a co-payment (\$5.80 concessional and \$35.40 general) for a cancer drug more than once e.g. only one co-payment per course of chemotherapy. The same should apply to private hospital treatment we understand.

In Victoria, cancer patients attending public hospitals for chemo are treated as inpatients, whereas NSW regards them as outpatients. Inpatients cannot be charged co-payments. We continue to be concerned about this anomaly.

Chemo Costs Watch

Let us know if you have been charged more than once, or more than the standard co-payment for any cancer related drug, during treatment at a public or private hospitals, as an "outpatient". This information will be most valuable for our discussions with the NSW Ministry of Health

NSW Legislative Council's Inquiry into the use of cannabis for medical purposes

Cancer Voices NSW made a public submission to this Inquiry, supporting the use of cannabis for medical purposes. We concluded :
"As advocates for people affected by cancer, and as a volunteer organisation comprised of people *with* cancer, we see our role as principally to examine and comment on what impact such use will have on people with cancer. We note that there is good evidence for major benefits, specifically for symptoms and side effects often not well managed now. We fully support the placement of controls which ensure appropriate prescribing protocols and safe and efficient delivery to people for whom it has been prescribed.

We also recognise that the drafting of potential legislation will need to deal with legal implications. We strongly caution against the introduction of more emotive arguments, such as political or religious views and/or beliefs. This issue is neither a political or religious matter – it is about deciding to allow access to a medicine, with due care to restrict such access to those who will benefit from it."

Consumer Reps Programs

The next Consumer Advocacy Training course will be held on 22 & 23 March, followed by another on 19 and 20 July. We look forward to welcoming keen new graduates to help with our ever increasing "voice" on decision-making committees, and in advocacy for the issues identified by people who have experienced cancer. *See the Noticeboard on page 2 for how to sign up for the two-day course.* We do recommend it! A CVN Executive Committee member always attends the first day's training to speak about our role, activities and opportunities – and to answer questions.

Who Do Consumer Reps Represent?

Cancer Voices NSW operates on Best Practice Principles of Consumer Participation (See Position Statement on our Website). When we nominate you as a Consumer Representative, it means we have confidence that you will be able to offer the broad view of people affected by cancer – as best you can – not just your own individual view. You are taking a place on a committee with a cancer consumer perspective – ie representing the needs and interests of people affected by cancer. You are not expected to offer a CVN organisational view, only the Chair, or delegated Office Bearers need to do that, and very occasionally.

Consumer Involvement in Research (CIR)

Matching researchers' requests for consumers

Cancer Voices' service to researchers, whereby we match informed consumers with their requests for consumer advice on their projects, has been extremely busy over the last few weeks. This is due to the annual cycle which requires grant applications to be completed and submitted to funders around this time. We remain hopeful, and keen to assist, a suitable national level organisation to take on this role for us, and for the other states which have similar needs.

Statement of Consumer & Community

Involvement (National Health & Medical Research Council and Consumers Health Forum of Australia). Sally Crossing has been working, with a committee of other consumers, on a revision of this important Statement. We hope to see it released before the end of the year, as it will provide very helpful advice to researchers and research funders on best practice for such involvement. This is increasingly important since most funders now require evidence of meaningful engagement with the consumer view.

Draft Consumer Engagement Strategy

Cancer Voices has developed a draft Consumer Engagement Strategy for potential adoption by research organisations and research funders. We are fine-tuning it with the Kinghorn Cancer Centre initially, and then will offer it more broadly. Its development is in response to researchers asking "what are we supposed to do in that area of consumer engagement?"

Publication – Consumer Research Priorities

Towards meeting the research needs of Australian cancer consumers : Carla Saunders and Sally Crossing, BMC Research Notes 2012, 5:667.

We are delighted that this paper is now available through publication by an Open Access peer reviewed international journal. It reports on developing a process for gathering cancer consumers' priorities for research, and what those priorities are, under five main research headings :

- Prevention & Risk
- Screening & Diagnosis
- Treatment
- Survivorship
- End of Life Care

The priorities identified can now be taken to research funding organisations and research institutions, so they may be aware of what people affected by cancer and the community want to see researched.

Many Cancer Voices members helped bring this about, both by attending the Consumer Research Priorities Forum, held with the Cancer Council NSW in 2009, and the Cancer Voices survey which prioritised the very long list of topics from the Forum. We should try to do this every few years to maintain its currency.

Cancer Institute NSW & Research

 The CINSW has widely advertised two positions: on its *Research Advisory Committee Grant Review Panel*. We would like to see appointment of consumers who have the kind of broad perspectives and links which Cancer Voices nominees are able to provide. We trust that several of you have replied with expressions of interest.

New CIR Resource from Cancer Australia

For those interested in becoming more involved in cancer research, and in particular clinical trial research (not as subjects, but as consumer representatives advising the projects) an excellent new website resource is now available at

www.consumerlearning.canceraustralia.gov.au

We highly recommend having a look at this website, which was developed with advice and input by consumers, including members of Cancer Voices around Australia. *More about this on page 8.*

The Voices Being Heard

Major Meetings

- NHMRC Consumer & Community Involvement Statement, Canberra, 23 Jan
- Medical Oncology Group of Australia, 29 Jan
- Royal College of Pathologist Australia, 30 Jan
- Royal Australasian College of Radiology, Faculty of Radiation Oncology, 7 Feb
- Joint Executives meeting, CVN and Cancer Council NSW, 20 Feb
- Cancer Directory Committee, CCNSW 22 Feb
- Cancer Australia, 21 Feb

Communications

- Electronic Christmas/New Year cards to all our stakeholders

- Congratulations to Dr Helen Zorbas AO and Prof Sally Redman AO, Aust day Honours

Submissions

- Medical Cannabis
 - Cancer Pain Management in Adults
 - Complementary & Alternative Medicines
 - TGA pre-market assessment *
 - Pharmaceutical patents *
 - MSAC Review*
 - Licensing of Patents*
- * denotes national issue, submitted under the banner of Cancer Voices Australia, co-ordinated through CVN.

Events & Forums

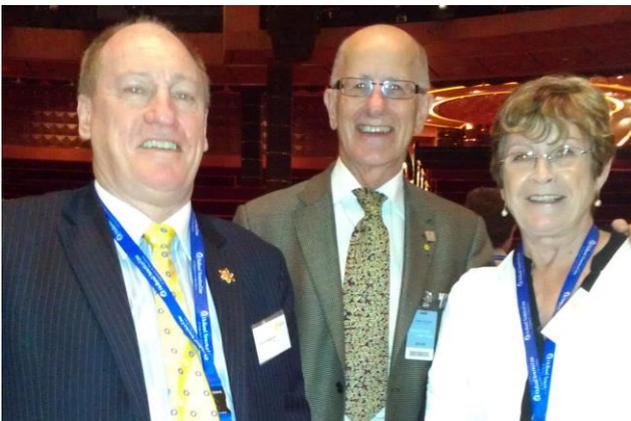
- National Indigenous Cancer Network Launch, 4 Feb

Media

- Sydney Morning Herald, 2-3 Feb News Review
- World Cancer Day 4 Feb, CVA media release
- Gene Patents Decision, 15 Feb; media release (CVA) and 12 interviews, numerous media reports; ABC Radio Health Matters 21 Feb

WELCOME ABOARD LUNCH

The Cancer Council NSW held a “Welcome Aboard” lunch aboard the MS Oosterdam for invited volunteers and advocates on 6 February, 2013. The lunch was hosted and donated by the shipping line. Each of their passenger liners will be holding a charity walk on each cruise to raise funds for cancer charities in five different countries. In Australia the Cancer Council is the charity nominated to receive proceeds from the walk. With approximately 500 cruises per annum and the cost of taking part in the very popular walks being \$20, CVN imagines this will be a welcome addition to donations.



Bruce Hodgkinson (Chair, CCNSW), Stephen Ackland (Board Member, CCNSW) & Kathy Smith (Chair, CVN)

Cancer Institute NSW

Brain Tumour Support and Education Forum

The Cancer Institute NSW will host the Brain Tumour Support and Education Forum on Wednesday, 1 May 2013 at The Menzies Hotel, Sydney. This free annual forum will coincide with Brain Cancer Action Week. Patients and carers as well as health professionals are welcome to attend.

The keynote address will be delivered by D. James J Vredenburg MD, a US specialist in haematology and medical oncology. Dr Vredenburg will also join local health professionals to discuss the latest treatments and support services.

Registrations are now open at

www.cancerinstitute.org.au/events/i/brain-tumour-support-and-education-forum-2013

About Rare Cancers Australia - RCA



Editor: CVN warmly welcomes Rare Cancer Australia (based in NSW) as a new member. Kate Vines has joined our Executive Committee, bringing rare cancer issues which might

benefit from advocacy to our table. This will benefit both organisations very much. For its part, CVN needs more knowledge about the specific issues for people affected by re cancers, and RCA is keen to seek our skills in the advocacy area.

Kate reports:

Rare Cancers Australia Ltd is a charity whose purpose is to improve awareness, support and treatment of Australians with rare and less common (RLC) cancers. Every year there are over 44,000 diagnoses of RLC Cancers and around 24,000 deaths. Because there are so many rare cancers and they have only small numbers of patients there has not been significant patient advocacy and support for many of these groups. Rare Cancers Australia aims to fill that need and our goals are as follows:

- **Patient Community** – A common reaction to a diagnosis of an RLC cancer is a sense of isolation, confusion and “aleness”. RCA is developing online communities and databases to ensure patients can both better understand their disease and readily meet and communicate with others experiencing similar challenges. See www.rarecancers.org.au
- **Patient Support** – A diagnosis of cancer often creates a number of related practical challenges

for patients as they undertake treatment for their disease. By identifying patient needs through social workers at oncology wards and facilitating assistance from volunteer and other organisations, RCA aims to ensure delivery of real practical support in areas such as domestic maintenance (gardening and cleaning), pet care and accommodation.

- **Treatment** – RCA is working to ensure that the best treatments in the world are available and affordable to Australian cancer patients. Recent breakthroughs in cancer treatment require reforms to the current government funding programs if Australians are to have access to the best possible care.
- **Early Diagnosis** – Early diagnosis is a key element in a cancer patient's survival prospects. RCA raises awareness with both the public and medical profession of rare and less common cancers and aims to greatly improve the likelihood of early diagnosis.

Rare Cancers Australia Ltd is classified as a Health Promotion Charity by the Federal Government. All contributions are tax deductible.

WHAT'S HAPPENING AT STATE LEVEL?

Cancer Council NSW

The CanAct Community of cancer advocates

Cancer Voices is happy to support opportunities for like-minded people to join together to make a difference in the cancer world. Cancer Voices members are invited to join Cancer Council NSW's **CanAct** community, which is a network of community advocates across NSW with a passion to change what politicians do about cancer.

Being part of the **CanAct** community means that you will be on Cancer Council NSW advocacy email list, to **be the first to know** about what they are doing in cancer advocacy e.g. Cancer Council recently welcomed the introduction of smoke free outdoor areas, an issue that they had been campaigning on for some years. 2012 also saw increased funding for bowel cancer screening, banning of solaria, and improvements to the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS).

CanAct has an informative website portal that was launched late last year and has information and news on cancer advocacy campaigns, training and events. It also provides tips and tools to help you take action on issues you care about. To find out more, and join the CanAct community, please visit www.canact.com.au

WHAT'S HAPPENING NATIONALLY?



Cancer Voices NSW has been very actively working on national level issues with our re-energised national group Cancer Voices Australia (CVA). These include :

- Chemo costs price disclosure
- Patents on human genes decision
- Treatment in private hospitals
- Survivorship Charter

Two media releases : World Cancer Day on 4 Feb, and the Gene Patenting Decision on 15 Feb.

Submissions : Medical Services Advisory Committee, the Therapeutic Goods Authority, Productivity Commission, and a Senate Inquiry. A lot!

Cancer Directories like Canrefer : CVA wrote to all Australian Cancer Councils recommending they develop cancer referral directories like the CINSW's Canrefer.

Gardasil for Boys: CVA welcomes the Health Minister's announcement that the Gardasil vaccination is now available for boys as well as girls.

We are working with Cancer Voices or similar independent cancer consumer organisations in the other states. The CVA Executive Committee has had meetings with the professional colleges representing medical oncologists, radiation oncologists, pathologists, and with Cancer Australia to reintroduce ourselves and discuss issues of mutual for possible action.

CVA is active on Facebook and Twitter and the web address is: www.cancervoicesaustralia.org

NEW CAMPAIGN!

Human gene patenting

We need to amend patent legislation

Cancer consumers were extremely disappointed by the Federal Court's ruling, handed down on 15 February in Sydney, which upholds commercial patents over human genes, in this case specifically the BrCa1 gene.

The Federal Court Judge accepted for the purpose of the decision that the material is identical to when it is in the body, but found that the fact that it is isolated by human intervention renders it a "manner of manufacture".

Cancer Voices welcome the public attention and outcry that this case has created around an issue which is extremely important in terms of ethics and equity – with impacts way beyond breast cancer genes.

The media have been asking Cancer Voices - how does this decision affect cancer patients? A reasonable question, which can be answered by saying it means that accessing the testing for these genes will become increasingly costly and slow. This is obviously not helpful for diagnosis, or the very difficult treatment decisions which a person must make once aware that they carry these genetic mutations.

Even more important than cancer, which is important enough as it is now Australia's number one killer, is the impact of other diseases with genetic markers. And it's important for research which needs faster and free access to this kind of genetic material in the new age of personalised medicine.

More important still is the ethical question for the community - do we really want bits of our bodies, bits with our building block instructions written on them, to be commercialised like this, do we want to live with "gene monopolies" (Ian Olver's perceptive term)?

Cancer Voices Australia, and the many people living with cancer today, call for an Amendment to the Patents Act which would exclude the ability to patent any human material.

We seek bipartisan support for this as the Federal Election heads towards us.

Check the Special Insert and see what you can do to add your voice to the

SAY NO TO GENE PATENTS CAMPAIGN



Cancer Australia

CVN is excited about these new cancer consumer resources, and is pleased that they both had extensive consumer input, including by people who are members of ours, as well as of other consumer groups. We recommend you check them out via their website addresses below, or via a Google search.

The first is most useful for consumers interested in becoming involved in research and will be a major resource for our CIR Program nominees, present and future. The second will be helpful for more general consumer representative and advocacy work.

World first consumer resources launched on World Cancer Day

Cancer Australia launched two new online multimedia resources to increase the involvement of people affected by cancer in cancer control efforts.



Prof Helen Zorbas

Cancer Australia CEO Professor Helen Zorbas said that World Cancer Day provided an opportunity to acknowledge the unique perspective that cancer consumers provide to improving cancer care and services.

The two new resources are :

- *The **Consumer Learning Website** which is designed to enhance consumer knowledge and confidence in contributing their perspective to cancer research and clinical trials. The website contains short online learning modules and video presentations to guide consumers who want to know more about becoming actively involved.*
- *The **Consumer Involvement Toolkit** will support CEOs, managers, health professionals, researchers and policy-makers to effectively involve consumers in their organisation's work. By providing practical, easy-to-navigate and user friendly tools, including case studies, templates and other time saving aids such as checklists, these organisations and individuals will find it easier to engage and involve people affected by cancer.*

“Increasingly, people affected by cancer and the broader community are seeking to take an active part in decision making about their health and these resources will assist in facilitating that consumer involvement,” Professor Zorbas said.

“The evidence suggests that involving consumers leads to improved health outcomes, a more trusted health system and a more satisfied workforce.

“There are many areas where the active participation of consumers has led to changes and improvements, including setting priorities for research, policy development and health service improvements.

“People affected by cancer remain at the centre of Cancer Australia’s efforts and the development of these resources provides some practical tools for consumers to have a voice in cancer control.”

Consumers, health professionals, researchers and policy makers from a range of health organisations from across Australia have been instrumental in developing the new resources.

*The **Consumer Learning website** was developed in collaboration with the Clinical Oncological Society of Australia (COSA) and is available at www.consumerlearning.canceraustralia.gov.au*

*The **Consumer Involvement Toolkit** was developed with the assistance of the Health Issues Centre and was based on the world first National Framework for Consumer Involvement in Cancer Control released by Cancer Australia in 2011. It is available at www.consumerinvolvement.canceraustralia.gov.au*

National Indigenous Cancer Network (NICaN)



Cancer survival is lower for Indigenous Australians than other people. It is the second leading cause of death among Indigenous people, accounting for a greater number of deaths each year than diabetes and kidney disease.

NICaN is a national network that encourages and supports collaboration around Indigenous cancer research and delivery of services to Indigenous people with cancer including their carers and families.

NICaN is about making sure that what's known about cancer in Indigenous Australians is available for use by people with cancer, their families, practitioners, policy makers and researchers.

NICaN has been set up as partnership between the Menzies School of Health Research, the DISCOVER-TT Centre of Research Excellence, the Australian Indigenous HealthInfoNet, the Lowitja Institute, Cancer Council Australia and Indigenous audiences, consumers, researchers and health professionals from a broad range of disciplines, service providers, private sector and government organisations.

When people register at the NICaN Yarning Place members will have the opportunity to participate in discussion forums, attend network meetings via Indigenous Cancer Roundtables, be kept up to date with research nationally. Please take a look at <http://www.cancerinfolnet.org.au> which holds the latest, most comprehensive collection of nationally collated information on Indigenous cancer control. NICaN is also on Twitter ! <https://twitter.com/NICaN2>



Teresa Leon (NICaN), Adelaide Saylor (Indigenous Breast Cancer Survivor), & Kathy Smith (Chair, CVN)

Cancer Voices NSW - Annual Report 2012

2012 began for Cancer Voices NSW with a change in the position of Chair when I replaced Sally Crossing after her 8 years in the position. Sally remains busy in her role of Deputy Chair working tirelessly on behalf of cancer consumers in NSW.

Activities were once again many and varied and our work of previous years began to take hold in 2012. Of particular note was construction of several Regional Cancer Centres, some of which came on-line to provide integrated cancer diagnostic treatment and care in areas previously denied equity of access. This is particularly the case with public radiotherapy services for which CVN has lobbied for many years.

In July 2012, the Executive Committee met to update and collate issues for people affected by cancer and identify areas needing CVN attention. These were listed in the September Newsletter for comment and feedback, and are guiding our current advocacy efforts. Issues raised by members continue to draw our attention e.g. concerns regarding adherence to best practice guidelines and protocols in private cancer clinics and hospitals being the most recent.

Highlights

At the AGM in February the “Inaugural Award for Excellence in Consumer Advocacy” was awarded posthumously to Sally Hodgkinson who contributed so much of her time and energy to ensure that the wheels of CVN ran smoothly, and was a much valued consumer representative.

2012 saw the restructure of Cancer Voices Australia with a return to the original aims and objectives for which the organisation was formed in 2007. CVN was integral in this process and we are pleased to be able to report that organisations representing many cancer types, states and territories are joining with the renewed national body to ensure the informed consumer voice is heard in Canberra. A bright future is envisaged for this integral part of the Cancer Voices network.

Consumer Representation

Nothing about us without us!

The end of December saw a total of 76 CVN nominated consumer representatives sitting on 176 committees of different types for 54 different organisations. This does not include the literature

reviewing activities for stakeholder organisations. There are 89 individual research projects within 22 organisations for which CVN provides consumer input. All consumers nominated to work with decision-makers by CVN are trained to provide the broad consumer perspective. They are not expected to speak for Cancer Voices as an entity. A very few stakeholders continue not to understand this important difference – a challenge for us.

Consumer Training

Three general Consumer Advocacy Training (CAT) Courses were held with CCNSW in Sydney, and their graduates invited to join Cancer Voices. A Consumer Involvement in Research (CIR) Training Course was held on 31 August-1 September and was well attended, and ensures ongoing quality consumer representation in cancer research through CVN's matching service for researchers seeking informed consumer input.

The Written Word

Quarterly 8-12 page newsletters were published during 2012 and mailed in hard copy as well as being posted on the website where they are searchable for reference/research purposes. Should more information be required on items mentioned in this Report, it can be found in the Newsletters.

Speaking Out

Members attended many workshops, seminars, conferences, etc. to keep themselves and the Executive Committee up to date on issues and projects as well as to provide the cancer consumer view to others.

I was fortunate enough to attend the European Cancer Patients Alliance conference in Rieti, Italy in June. This was made possible by a bursary from the organising committee and the generous gesture from the NSW Cancer Council who covered the cost of my airfares and accommodation.

In September we presented a poster “Cancer Consumers Innovate” at the Cancer Institute NSW “Innovation Conference”. The poster was also presented at the COSA conference in Brisbane in November. Sally presented on the topic “Consumer Involvement in Research” at the Sydney Cancer Conference in September and to other research organisations on request. Other attendances are too

numerous to include in this report but details can be found in the Newsletters for 2012.

Electronic Communications

2012 saw CVN take the step of becoming a part of the Facebook world. The address is <http://www.facebook.com/cancervoicesnsw> for anyone wishing to follow us.

Organisational

At December 2012, Cancer Voices members numbered 73 cancer support and advocacy groups (voting members, some of which have several hundred members), 319 individuals and 139 Associate and “for information” members.

Our AGM will be held on 6 February 2013. We remain an entirely independent and voluntary organisation; our success depending on the efforts of members, consumer representatives and particularly, members of the Executive Committee.

Financial

The Treasurer’s Report for 2012 will be presented separately. The valuable volunteer work of members, of pro bono services such as newsletter printing and mailing by the Cancer Council NSW help keep expenses down. Regrettably, we no longer receive financial assistance from the Cancer Institute NSW. The pro bono work in 2012 on behalf of CVN by McCabe Lawyers to protect the use of the trademarked name “Cancer Voices” was invaluable in ensuring the future direction of the Cancer Voices network and its associates is protected in Australia.

Executive Committee 2012

The Executive Committee met every six – eight weeks at the CBD offices of UBS Investment Bank (also pro bono), and out of session as necessary. Members this year were Sally Crossing (Deputy Chair), Jane Barrett

(Minutes Secretary), Sandra O’Sullivan (Co-opted Treasurer), Elisabeth Kochman, Bev Noble, Peter Brown, Tony Maxwell, Martin Berry, Roberta Higginson and Kathy Smith (Chair). Sadly, Jane lost her struggle with CUP and died on 12 July. A true loss to her friends and colleagues at CVN.

Reflection and Thanks

As CVN moves into another year, I would like to thank all our members and especially those who have contributed to the organisation in varying ways. Input is always welcome and I would certainly like to encourage members who are in a position to do so, to attend the Executive Committee meetings held in the Sydney CBD.

Maybe you would like to meet your Executive Committee and see what takes place at meetings. You may hear something that will raise your interest in taking action with us.

Thank you also to those who made financial donations in 2012. These donations (tax deductible) help to make sure CVN is in a position to operate in an effective way.

As always, thanks go to the 2012 Cancer Voices NSW Executive Committee and the effective and informed consumer representatives working on behalf of NSW cancer consumers. And, of course, thanks again to our stakeholders and partners for their support, encouragement, inclusivity and respect.

Kathy Smith

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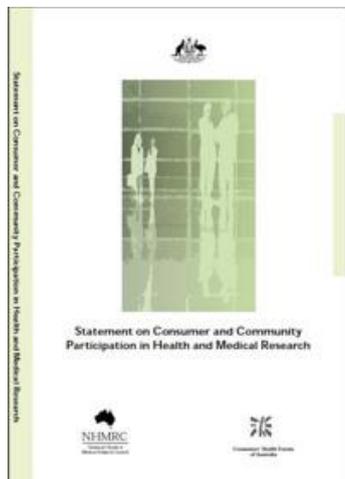
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From Consumers Health Forum of Australia

Consumers want to be involved in health and medical research

The Joint CHF/NHMRC Statement on Consumer and Community Participation in Health and Medical Research is being revised and strengthened.



More than ten years ago, CHF and the National Health and Medical Research Council (NHMRC) developed a *Joint Statement on Consumer and Community Participation in Health and Medical Research*, designed to support consumer and community participation in research. The Statement has been reviewed, and at a national workshop to discuss the revised Statement in December, it was clear that consumers want to be more involved at all stages of the research process – not just as the subjects of research. Consumers made strong recommendations about how to ensure consumers and community members are more involved in research, including making consumer involvement a requirement in applications for government research funding, and increasing involvement of consumers in the allocation of research funding. The revised Statement will be released for further consultation later this year.

Room for improvement in informed financial consent

Informed financial consent (IFC) is an issue of critical importance for many health consumers, and consumers reported a range of experiences with IFC, both positive and negative, at a national consultation as part of a CHF project funded by the Bupa Health Foundation. The inconsistency of consumers' experiences across different health care settings, jurisdictions, and sometimes even within the same setting over time was identified as a major problem. Consumers strongly recommended that appropriate policies, standards and procedures are put in place to achieve greater uniformity across the health system, so that consumers are not faced with high unexpected out of pocket costs.

*Cancer Voices NSW provides the independent voice of people affected by cancer in NSW
To improve the cancer experience of the 40,000 people who are diagnosed each year
Established in 2000, we focus on 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*

THANKS !

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