

Message to Members

The year has gathered much momentum. We have a new State Government and lots of questions about how cancer services will be supported under the new health service structures. Keeping in mind the interests and needs of people affected by cancer, our principal areas of action this quarter have been following up:

- Recognition, maintenance and support of the well developed cancer networks in NSW.
- Restoration of diminished palliative care services in NSW.
- Isolated Patients' Travel & Accommodation Assistance Scheme (IPTAAS) reforms and improvement.
- Confirmation of the Cancer Institute NSW (CINSW), its activities, funding, and relationship to Government.

Cancer Services in NSW

We have heard of confusion about the future of cancer services from those providing them. As a result, we have focussed on seeking reassurance from the Office of the NSW Minister for Health, the Hon Jillian Skinner MP, that existing cancer networks and how cancer services will be supported under the new health service structures.

Keeping in mind the interests and needs of people affected by cancer, our principal areas of action this quarter have been following up: devolution process to the new 15 Local Health Districts. We have heard of confusion about the future of cancer services from those providing them .



CVN Executive Committee 2011: *Back row Bev Noble; Jane Barrett; Tony Maxwell; Sally Crossing AM; Peter Brown; Elisabeth Kochman; Seated Sally Hodgkinson and Kathy Smith. Yvonne McMaster missing (see photo on page 8).*

As a result, we have focussed on seeking reassurance from the Office of the NSW Minister for Health, the Hon Jillian Skinner MP, that existing cancer networks and comprehensive cancer centres will not be adversely affected by the devolution process to the new 15 Local Health Districts. While this has not been suggested, we are keen that the advances made in cancer treatment in NSW over the last few years, mainly due to the advent of higher volume, specialised cancer centres using multidisciplinary teams, are maintained. Our second principal thrust is the reinstatement and funding of appropriate palliative care services. Yvonne McMaster has been leading this campaign, with assistance from the Cancer Voices NSW team - more detail about this inside.

Consumers and Research

Reviewing a new book about cancer research and treatment, Norman Swan (Spectrum SMH 21-22 May) said "*The real heroes of this story are the people with cancer who need a seat at the table to keep researchers focused on the main game. The future of cancer has to be about care, cure and selfless collaboration*". We completely agree and accept the challenge!

Space too bigCVN has been thinking about the future of our service to cancer researchers by matching their requests for informed consumers with our own database of graduates of the annual Consumer Research Training, held in conjunction with the Cancer Council NSW. This is in some doubt now that the Cancer Council has decided not to hold this course, at least in 2011, an unexpected disappointment. Ideally, we would like to hand over this service to an independent national organisation - one in which we had confidence in doing it well, without any conflict of interest. The service would need to be properly funded and promoted.

Cancer consumer advocacy training continues apace - see Noticeboard page for the next set of dates. New "CAT" graduates of the 3-4 June course are most welcome to join CVN and will help us ensure the voice of people affected by cancer in NSW and beyond is heard.

Please keep your issues coming in, either as group or as individual members. Cancer Voices NSW is membership-based, as a health consumer organisation should be. The more we hear from you, our constituents the better armed we are for making that positive difference.

Best wishes

Sally Crossing AM, Chair

CVN NOTICEBOARD

Learn about advocacy, and how to commit it!

Last Consumer Training CAT courses for 2011

19th & 20th August 2011

16th & 17th March 2012

then

25th & 26th November 2011

18th & 19th May 2012

To apply and to check venues, please head to <http://www.cancercouncil.com.au/advocates/workshops>

Or contact the Cancer Council NSW (Policy & Advocacy) on 02 9334 1406 or

advocacy@nswcc.org.au to be sent an application in the mail.

Cancer Voices NSW recommends that anyone interested in taking part, speaking up, developing and promoting policy for improvements, writing about their ideas or concerns, being a CVN consumer representative on committees, working parties etc - in general joining the action to improve things for people affected for this excellent introductory course

CVN's Consumer Involvement in Research (CIR) Program

Annual Consumer Research Training: We regret to advise members interested in becoming involved in cancer research that this course, previously advertised for 8 & 9 September, has been cancelled by the Cancer Council NSW, our partner in presenting it. Cancer Voices NSW will consider mounting a course on its own, and will advise in the September newsletter. This training underpins our ability to "match-make" informed consumers with researchers who are looking for them to assist with consumer input. **Keep in touch.**

Meanwhile, please let us know your contact details to confirm our lists are up to date, if you remain interested in being a consumer representative in the CIR Program (this applies to newly interested and those who have graduated from previous years' training courses). Email info@cancervoices.org.au

CVN Committee News

The CVN Executive Committee met on 6 April and 25 May 2011. We welcomed Martin Berry as a co-opted member of the CVN Executive committee - Martin replaces Kate Tynan.

We are still short of someone who can contribute the colorectal cancer view, so let us know if you are interested and come to the next meeting to see how you can help others like you.

CVN members interested in being a part of the CVN Committee are most welcome to join us for a meeting or two to see how it works - we are always keen for new ideas and skills.

Newsletter: CVN will continue to publish its Newsletter each quarter to alert members to its activities on their behalf and to invite input into its direction. Sally Crossing remains Editor, Sally Hodgkinson formats and Elisabeth Kochman our trusty proof reader. Thanks, as ever, to the Cancer Council NSW for printing and mailing it to you on our behalf. This is very valuable pro bono assistance.

Sally Hodgkinson, our valued Hon Secretary, Database & Reps Manager and newsletter formatter has been having a bad time with her cancer over the last few months. However, not daunted by periods when walking defeated her, punctuated by a couple of falls and a hip replacement operation, "Sally H" has continued her various roles for CVN, often from her hospital bed. Talk about beyond the call of duty! We thank her for keeping on keeping on, and wish her speedy return to a good QoL.

Membership: They are currently 86 group (voting) memberships and 332 individual members.

CVN CONSUMER REPS IN ACTION

"Nothing about us without us!"

Consumer Reps Program Report-

Overall Consumer Representation: We service a total of 136 committees of different types and 67 nominated individual consumers sit on these committee for 51 different organisations. (This does not include the reviewing activities for organisations such as the Cancer Council NSW, NBOCC, NBCF etc.)

Research Projects: There are 72 individual research projects within 24 organisations for which CVN provides consumer input.

Most of the demand for consumer input comes towards the end of the year/early New year, when

researchers are assembling their applications for grant funding either from the NHMRC; Cancer Australia; or State Cancer Councils, NBCF & PCFA all of which now require consumer input at varying levels. So if you are interested in being involved please let us know.

Keeping the database up to date

CVN thanks those few who responded to our request in the march Newsletter. We asked our valued band of consumer representatives to give us news of their committees, activities and interests. We need to keep up to date with representatives who work as a CVN nominee. The process is that organisations request our help in providing them with the consumer perspective through the Cancer Voices NSW website. We then "match-make" the request with our database, then email you their request form with its details to see if it interests you. Quite often, our requesters forget to let us know when the committee or project has ended. We also want to improve our Reps Program for you, for CVN and for our requesters.

This process would be much quicker if we had a full set of up to date email addresses for our over hundred trained reps, so please email info@cancervoices.org.au today.

Consumer Advocacy Training

Welcome to new CVN "graduate" members!

There have been three CAT course this year, in March, April and June. Check the Noticeboard for planned dates for the rest of 2011 and into 2012.

We warmly welcome those new "graduates" who have joined Cancer Voices as a result of their training, particularly the very enthusiastic group who attended the Young course in April. It's great to have you on board, especially from your part of NSW. This will be your first newsletter as members - please let us know of issues you would like to raise with us. We have added you to the database of trained consumer reps and will offer you a role when suitable requests are made to us.

CAT courses for 2011

Cancer Voices NSW recommends that anyone interested in taking part, speaking up, writing about their ideas or concerns, being a CVN consumer representative - in general joining the action to improve things for people affected by cancer, should sign up for some kind of advocacy training.

See Noticeboard for dates.

To express interest in future training, please head to <http://www.cancercouncil.com.au/advocates/workshops> or contact the Cancer Council (Policy & Advocacy) on 02-9334 or advocacy@nswcc.org.au to be sent an application in the mail.

Advanced Consumer Media Training

CVN funded the attendance of two of its most active consumer advocates and media stars, Kathy Smith and Yvonne McMaster, to attend an advanced media training day run by PIAC on 23 May.

We are always looking for new and enthusiastic Reps! Let us know your interest directly through info@cancervoices.org.au. Check out training opportunities listed above.

Who are you representing?

Cancer Voices NSW operates on Best Practice Principles of Consumer Participation (see Position Statement on 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 be offering a Cancer Voice organisational view - only the Chair, or delegated Office bearers need to do that and very occasionally.

Position Statements have been updated and new ones are under consideration. See www.cancervoices.org.au. They are developed to help inform our partners and stakeholders of the views of people affected by cancer in NSW on a range of important issues. They are developed in consultation with our members, usually at our member's suggestion and provide our reps with a summary briefing. So if you or your group has an issue that would be suitable, let us know.

AREA Cancer Services (ACS) REPORT

The Area Cancer Service Reps met by teleconference on 29 March and 24 May, timed to inform the next CVN Executive Committee meeting, so that outcomes can be factored in. We understand that although the Area Health Services have disappeared, the "Area" Cancer Services and their Directors will remain in place. We are hearing there is some confusion about just how the existing cancer networks will operate across more than one Local Health District, and how existing services will be retained after "devolution" to the new Districts. CVN has sought clarification of the situation from the Cancer Institute NSW and the Minister for Health.

New Health Districts from 1 July 2011

We will be looking for CVN Reps from each of the new 15 Local Health Districts, who would like to join these free (no cost to your telephone account) teleconferences to offer the views, news and needs for people affected by cancer in their area. Of course, you can also do this by mailing or emailing us at any time.

Contraception & Cancer Drugs

Annette Clement from Hunter & New England raised the issue of a major Catholic Hospital not providing information about medically necessary contraception for some cancer drugs. This issue gained considerable traction in the *Sydney Morning Herald* of Monday 6 June, 2011, on page 3

Consumer Involvement in Research (CIR) Program

New website resource: Involving people in research

<http://www.involvingpeopleinresearch.org/>

This website has been developed to house resources such as the new Fact Sheet Series <http://www.involvingpeopleinresearch.org/index.php/resources/fact-sheets>

And will eventually provide a 'one-stop-shop' to support increased consumer and community participation in health research.

We hope you find this website a useful tool in your endeavours to increase participation. Over the next few months we will be adding lots of new materials and resources such as publications, good practice examples, stories and links to other useful websites. We look forward to your feedback as the website develops.

Anne McKenzie, Hayley Haines and Rachel Skoss

(Editor's Note: This is a University of WA group I have worked with closely over the years, and will be meeting up with again while in Perth on 31 May. They are also keen to promote a national support centre for consumers involved in research. These Fact Sheets are excellent - and will help all consumer reps, although specifically designed for those involved in scientific and medical research.)

NMHCRC - Updating Consumer Engagement Statement

The National Health & Medical Research Council (NHMRC) has an annual budget of approx \$750 m and is the major Australian public funder of this kind of research. Cancer is a national priority health area and cancer research grants attract more funding than others (followed by cardiovascular and prevention), which is good news for us.

In 2003 with the Consumers Health Forum of Australia, the NHMRC developed and published a Framework and Statement and to assist researchers engage with consumers to improve the value of research. A lot has happened since then. Many researchers seeking grants are now required to show meaningful engagement with consumers, but are not sure where to turn to find them. The CVN "match-

making” program addresses this demand in NSW and beyond if necessary, as does the BCNA (Breast Cancer Network Australia’s) “A Seat at the Table” process.

On 19 May, Sally Crossing was invited to attend a Canberra Workshop on Consumer Engagement to assist the NHMRC’s project. She made a short presentation about our Consumers Involvement in Research Program and gave them a copy of our COSA 2010 Poster, which summarises its six major elements. NHMRC will use this as a case study of practical processes and achievements in implementing consumer involvement in research. CVN’s implementation and practice is recognised as “gold standard” around the traps, and we are most willing to share what we have learnt and developed.

We, and others, raised the issue of needing a national unit to co-ordinate the provision of trained and informed health consumers, networked with others, who wished to assist medical researchers. This concept received a lot of support.

Consumers’ Research Priorities

A paper discussing the ultimate priorities and gaps identified by consumers in 2009 has been submitted for publication, authors being Carla Saunders & Sally Crossing. Thanks to CVN members who participated in the original Consumer Research Priorities Forum and those who answered our survey questions late last year. This paper will be of considerable value to us when promoting the research priorities to research funders, and to organisations wanting to know how to ascertain what our research priorities are.

Cancer Voices NSW’s Twelve Point Research Plan

Cancer Voices NSW has been encouraged to take a greater interest in improving the direction and scope of cancer research for the benefit of the end beneficiaries (US!).

The statement below, a wish list really, is the beginning of our thoughts on what needs to be done. Some of these have been nibbled at, but we are requesting that a comprehensive review would look at the full range of suggestions. This will become a CVN Position Statement, following draft exposure to our members in this newsletter, so please let us know what you think. We will use the final product in advocacy to Government and major research funders towards strategies which will shape the direction, scope and processes of cancer research.

We in CVN would like to see national discussion and possible action on the following:

- Establishment of a national organisation which identifies research priorities & gaps to be funded, within a national cancer research plan
- Identification of significant gaps between cancer burden and kind of cancer research undertaken

- Mandatory registration of clinical trials on the ANZCTR
- Reversal of declining level of clinical trial activity in Australia
- Requirement by funders that informed consumers be involved in research, from concept to dissemination.
- A national register of trained, informed consumers to fill researchers’ requests
- Mechanisms to assess the question “Is this study really needed?”
- Increase in participation levels in Australian clinical trials
- **Broad promotion and use of Australian Cancer Trials Online to assist consumers and clinicians seeking consumer friendly info about clinical trials**
- Options for more public investment to support non-pharma industry trials groups
- More investment in research and trials which improve care, but may not translate to marketable interventions
- Continue to streamline the ethics approval process, eg centralising for multicentre trials

Website Requests & Interaction

Consumer Reps requests: To request a consumer representative for your organisation or group, please complete the form online.

To apply for membership of Cancer Voices, either as an organisational representative or as an individual member please download the following form [Membership Form](#).

Other Features

- All Cancer Voices NSW newsletters are held on our website and are searchable.
- 26 Position Statements about matters of interest for CVN members are posted and updated
- For cancer without support groups, use the website to bring people together - see “.....

INTERACTION ACCESS: To restrict the amount of spam, you must be a registered user of this wiki to use the online option. To request a user account, please send an email to info@cancervoices.org.au

Interactive Discussion: If you would like to contribute and take part in discussions with Cancer Voices (NSW) through our web site, www.cancervoices.org.au you will need to be registered.

To register and receive your username and password, please send an email to info@cancervoices.org.au requesting registration. You will receive an email in reply, usually the next business day, detailing your allocated username and password. We are doing this for security of website discussions reasons, mainly to keep out undesirables. So do give it a try and tell us what you think or what you need!

CVN ADVOCACY UPDATES

Two more regional cancer centres for NSW

Cancer Voices NSW welcomes the Australian Government's announcement that it would provide substantial funds for a comprehensive cancer centre at Albury (\$65 million) as supported formally by CVN last year. Tamworth will also receive \$31.6 million for a cancer centre.

Cancer Voices NSW - Issues Briefing

For meeting with Office of NSW Minister for Health, 17 April 2011

Cancer Voices NSW (CVN) provides the independent voice of people affected by cancer, working to improve the cancer experience of the 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 providers of these services, ensuring the patient perspective is heard.

Cancer is the biggest killer of Australians, and its incidence is rising as our population ages. Earlier detection and treatment through multidisciplinary teams working in comprehensive cancer centres have meant improved outcomes over the last ten years.

In 2010, CVN celebrated a decade of working with cancer world decision-makers and is keen to continue to do so with the new NSW Government and its agencies. We wish to discuss four major issues for NSW people affected by cancer:

1. Recognition, maintenance and support of cancer networks in NSW

NSW Cancer services and cancer outcomes have improved markedly over the last ten years, following a major review, Optimising Cancer Care in NSW, 2003 and the subsequent establishment of the Cancer Institute NSW in 2003. Cancer Voices provided the consumer view in both these turning point decisions.

NSW cancer policy and implementation have reflected international and Australian evidence which demonstrates that cancer service are best delivered at recognised comprehensive cancer centres, wherever possible, and with networks linking services to areas beyond these centres.

CVN seeks reassurance that the new Local Health District structure will not change the cancer networks system developed and funded by state and federal governments.

2. Continuation of the CINSW, its activities, funding, and relationship to Government

The success of the CINSW has been demonstrated by better outcomes of NSW people diagnosed with

cancer (approx 40,000 pa and rising) since its establishment. CVN understands there may be attempts by NSW Health to remove the present "arms length" relationship, regarded as an underlying reason for its success.

CVN notes there is no longer a Minister for Cancer and recognises that there is no need for such a portfolio, as long as the CINSW is maintained and supported. We have previously been assured that there is no intention to reduce the role, funding or structure of the CINSW, but would appreciate advice that this remains the view of the Minister.

2. Continuation of the Cancer Institute NSW (CINSW), its activities, funding, and relationship to Government

3. Restoration of diminished palliative care services in NSW

The Minister is aware of the shortcomings of palliative care services in NSW. As approx 85% of palliative care patients have cancer, CVN has a major interest in adequate funding and provision of palliative care services at community, hospital and hospice levels.

We recommend that NSW palliative care services be funded in a quarantined manner, and be provided according to mandated standards.

4 Isolated Patients' Travel & Accommodation Assistance Scheme (IPTAAS) reforms and improvement

In Opposition, the new NSW Government promised a series of reforms to IPTAAS, a Scheme which has proved advantageous to patients who, due to lack of local services, have needed to travel to receive treatment, including cancer patients who often need to access distant services or clinical trials. CVN looks forward to working with Government to improve IPTAAS.

A Decade of Success

Our much anticipated record of the first ten years of Cancer Voices is now in the design stage. We very much hope we will be able to mail you a copy of the 48 page booklet in the next month or two. Thanks to all who contributed - you are immortalised !

Cancer of Unknown Primary (CUP) News

The Sydney Morning Herald published an article on cancer of unknown primary in February this year. Jane Barrett, a CUP survivor, is a member of Cancer Voices NSW and has been advocating for CUP since October 2009.

<http://www.smh.com.au/lifestyle/wellbeing/lost-in-cancers-great-unknown-20110223-1b5o4.html>

Jane has established a new group - CUP Action - cancer of unknown primary under the umbrella of Cancer Voices NSW If you have been affected by CUP

in some way and wish to help with this advocacy work, please contact Jane at cupaction@gmail.com

Saving research funding in the Federal Budget.

Cancer Voices NSW gladly joined the Discoveries Need Dollars Campaign (see www.discoveriesneeddollars.org) to persuade the **Federal Government not** to cut the research budget by \$400 million as was threatened during the lead up to the May Budget announcement. We wrote to polities, used the campaign website and made our support clear. A lot of others joined this campaign, including researchers themselves who marched against the cuts in capital cities.

CVN has received several letters of appreciation of our support, especially noting that from the Victor Chang Cardiac Research Institute - very nice indeed.

Palliative Care Campaign

1. State-wide Palliative Care update

CVN has written to the new Minister for Health, with copies to other major players in the delivery of NSW palliative care services, to ask them to address the current very unsatisfactory situation. We are aware that the Minister and the Premier have the issue on their radar and that they recognise the role of Cancer Voices NSW in this campaign.

CVN will be meeting the Director and Clinical Advisor of the State-wide Centre for Improvement of Palliative Care (SCIP) on 7 June to receive a report of their review and to discuss our concerns and their plans to address the situation in this state.

2. Palliative care community service funding cuts in Northern Sydney

The campaign to restore palliative care community service funding to Northern Sydney following the 40% cut in 2009 is gathering pace.

There has been good media coverage with the local papers (North Shore Times 25.2.11, 4.3.11, 25.3.11 & 7.5.11) Hornsby Advocate (24.3.11 & 14.4.11) and Mosman Daily 10.3.11 & 13.5.11) getting into the swing and doing repeat stories. This is having some impact on both the politicians and senior bureaucrats in the Northern Sydney Local Health Network (NSLHN). On April 14, Bev Noble (Executive Committee Member CVN) and I met Susan Pearce (Director of Operations, NSLHN), Mark Newton (Director Population Health, Planning and Performance of NSLHN) and Karen Gill (Palliative Care Development Officer, NSLHN). Whilst they made several excuses for the withdrawal of funds and wished that Hammond Care might pick up the tag for them, they undertook to meet with Hammond Care.

This was my second meeting at the NSLHN, the first being with Professor Carol Pollock, Chair of the

NSLHN's Governing Council on March 14.

We have had sympathetic replies from both the Premier, Barry O'Farrell & Health Minister Jillian Skinner before the recent State election and continue to be in very regular touch with Barry O'Farrell's office. They have recommended 8 June as the closing date for our petition, so that the Premier can present 10,000 plus signatures to Parliament & initiate his promised debate. He is sending out copies of the petition to people complaining about the cuts and will meet with Jillian Skinner. Our petition asks the State Government to restore and improve funding for palliative care community services in Northern Sydney and to improve funding for palliative care throughout NSW. Signatures in early June totaled 23,000.

I have met The Premier the Hon. Barry O'Farrell and have either spoken to, or communicated with all the State politicians whose electorates have been affected. Jonathan O'Dea (MP for Davidson) made a Private Member's Statement to Parliament about the cuts and supporting the campaign to have funding restored. This speech (3.5.11), reported in the NS Times and Mosman Daily, has led to increased interest and awareness in the community and helped with the collection of signatures.

I have also met with Paul Fletcher (Federal Member for Bradfield) and Philip Ruddock (Federal Member for Berowra). Paul Fletcher has been most interested, writing two letters to the NSLHN as well as letters to the Minister and Hammond Care. He subsequently met with Hammond's top executives and is in follow-up correspondence with Vicki Taylor, CEO of the NSLHN. Philip Ruddock said he would meet with Paul Fletcher to move things forward.

Some surprising figures came to light during my research. I now realise why my Cancer Support patients are having such a bad time with respect to the palliative care community service. Since the funding cuts the community palliative care services to Neringah's area have dropped dramatically - from 181 community patients before the cuts in 2009, to only 78 two years later.

- Calvary Community Service (based in Kogarah) currently has 280 patients on its books and employs 9 nurses to look after them: an average of 31.1 patients per palliative care nurse.
- Similarly Sacred Heart (Eastern Suburbs) currently has 180 patients on its books and employs 11 nurses to look after them: an average of 25 patients nurse per palliative care nurse.
- In March 2009, before the funding cuts took hold, Neringah employed 3 palliative care nurses and had 181 patients on its books, an average of 60.3 patients per nurse. **Thus, even before the drastic**

cuts in 2009, the Palliative Care Community Service was inadequately resourced!

Yvonne McMaster



Yvonne and her petition (source *North Shore Times*)

The Voices being heard

The activities below are listed to give an idea of our various involvements during the quarter. CVN's nominated consumer reps attended a number of other regular committees and research project meetings as well.

Submissions:

Our Health, Our Community for Consumers Health Forum of Australia
Transparency of Therapeutic Goods Administration
Human Gene Patenting Bill
National Framework for Consumer Engagement in Cancer Control
PBS Deferral Decision, through CHF
Public Listing of Radiotherapy Waiting Times
Palliative Care Cuts and Services

Speaking:

“CAT” course 3 & 4 June

Major Meetings:

Minister for Health: Cancer Policy Officer, 27 April
Amalgamation of CA and NBOCC: Consumer Forum, 12 April
Macquarie University Hospital Cancer Centre
Cancer Council NSW - Joint Executives, 18 March
Cancer Council NSW - Post election meeting, 25 May
Cancer Australia - Consumer Framework, 13 April
Cancer Australia - National Reference Group / Framework 29 March

Cancer Australia - ACTO promotion 1 April
CINSW - Plans for Consumer Training, 28 April
CINSW - Cancer Services Directory, 12 April
CINSW - NSW Oncology Groups Executive, 3 May
CINSW - Clinical Services Advisory Committee, 16 March; April & June
NSLHN - Palliative Care, 14 March see previous item.

Events:

Cancer Council NSW Research Awards, 28 April
PMRI Lunch at NSW Parliament House, 29 April
Rotary International - Sally Crossing received an Award as a Finalist, Inspirational Women Award 29 April
International Women's Day, Government House, Canberra, 8 March
NHMRC Consumer Engagement Workshop, Canberra 19 May

Publications / Media:

Palliative Care: Yvonne McMaster, 14 articles in local papers; CVN media release, 30 May
Frontier, Macquarie University Hospital (Autumn 2011) - three page article about CVN
SMH CUP Action, Jane Barrett



Sally Crossing AM being presented with her award as a finalist in the Most Inspirational Women Award from Rotary International.

Change of Address

If you change your address, please let us know.
We do not want to lose you

Our contact details are on page 12

New members always welcome see website for membership application form

Cancer Council NSW

Cancer Council NSW Research Awards announced

The Cancer Council NSW Research Awards were held on 28 April 2011, with 120 researchers, supporters, Cancer Council staff, Consumer Review Panel members and Cancer Voices NSW representatives gathered to hear about Cancer Council NSW achievements in our research grants over the past year. They also witnessed the official presentation to researchers who were successful in latest round of grant applications (2010), with an award to signify the start of their research in 2011.

Consumer participation in research was a strong theme throughout the evening, with Prof John Rasko describing the unique contribution of the Consumer Review Panel and recognition from Dr Andrew Penman, CEO Cancer Council NSW, for the hard work of the Panel, in particular the current Chair, Mr James Butler, a CVN member.

The Cancer Council NSW is the largest funder of cancer research outside government funding agencies in NSW. It currently funds 67 Grants of which 20 are new Project, Program and STREP Grants, which brings the total value of the external grant portfolio to more than \$37 million over the life of the grants. Cancer Council's research portfolio is a significant investment of donor funds, and in which consumers play an integral role in the decision-making process.

Saving Life: why wouldn't you?

Leading up to the NSW state election, **Saving Life: why wouldn't you?** was the question Cancer Council NSW posed to MPs and candidates, with five key issues of community concern, noted in March CVN Newsletter.

Over 9,000 community members across NSW contacted their MP to pose the question of saving life. Thirty-three communities, including six Aboriginal communities, held Community Conversations discussing how the Saving Life issues were affecting people within their communities. *(Editor: CVN met with CCNSW and other stakeholders on 27 May to discuss next steps)*

Addressing the cost of cancer

The Cancer Council Legal Referral Service has grown strongly since its start in March 2010 and is having a significant impact on cancer patients and carers by helping them access legal services when they cannot pay for advice. To date it has provided assistance to over 800 clients, and almost 150 law firms are now registered to participate. The service is currently available in NSW and South Australia, and a roll-out in Victoria is planned for July 2011.

Clients can be referred by their social worker, or by calling the Cancer Council Helpline on 13 11 20. If

Cancer Voices NSW has members or contacts that may need legal support, please refer them to the Cancer Council Helpline. The service can assist with a range of issues, including wills, powers of attorney, early access to superannuation, mortgage hardship, employment, discrimination and tenancy. Clients who cannot pay for advice are eligible for free help, and all are assisted by lawyers acting pro bono through the service.

Supportive care for people with brain cancer

Brain cancer is one of the least understood and most under-studied of all cancers - it has been described as a 'black box' disease. While survival rates for most cancers have improved over the past decade, survival rates for brain cancers have not. It carries the highest financial burden of all the cancers, yet brain cancer research is grossly underfunded and few resources exist for patients and their families.

Cancer Australia awarded Cancer Council NSW a grant to develop a multimedia support network that specifically addresses the needs of patients of low-incidence, high-morbidity and high-mortality cancers like brain cancer. The **Brain Cancer Multimedia Support Network** will be the first integrated multimedia consumer support network in NSW for all affected by brain cancer - patients, carers and families, regardless of where they live. It will provide social networking, online support, printed information, telephone and carer support.

The website (visit www.braincanceraction.com.au) will expand in response to the needs of patients and family members. Cancer Council NSW would like to hear from anyone who is directly affected by a brain cancer diagnosis - whether you have been diagnosed, or you're a family member, carer or friend. A brief questionnaire "Brain Tumour: Service and Resource Survey" has been developed and can be completed online at www.braincanceraction.com.au (see the "Have your say" section). If you prefer, you can request a hard copy of the survey (a prepaid return envelope is also included) by calling the Project Manager on (02) 9334 1910 or emailing angelap@nswcc.org.au

Cancer Institute NSW

Latest cancer information now just a click away

A new look website from the Cancer Institute NSW will place the most important information on cancer at the fingertips of patients, clinicians, researchers and the general public.

The new website is a substantial upgrade from the current Cancer Institute home page. All content has been completely re-written and is presented in a concise format that is easy to understand, regardless of your knowledge of cancer. The result is a much more user-friendly destination that can host diverse and advanced web content. New features include:

- A new 'cancer in NSW' section that contains all the facts, figures and trends related to cancer.
- A brand new patient support section with questions and answers from prominent experts on cancer.
- An archive of all publications and journals published by the Institute and associated researchers.
- A new campaigns section with embedded videos and campaign material.
- Social media friendly options

The new website will be launched soon so keep a look out for it at www.cancerinstitute.org.au

WHAT'S HAPPENING NATIONALLY?

Federal Budget 2011

The most welcome news is the additional funding of \$104M to expand access to some Magnetic Resonance Imaging (MRI) services. CVN and CVA have waged a lengthy campaign on this issue.

From next year GP's will be able to refer children direct for MRI, the following year adults as well. In addition, 60 additional licences will be given for MRI services with many of these licences being supplied to the areas of most need.

Australian Cancer Trials website - now for awareness

www.australiancancertrials.gov.au

Cancer Voices NSW initiated the concept of a consumer friendly website about cancer clinical trials. Through Sally Crossing, a Chief Investigator on the NHMRC study which funded the project around the website, we had ongoing input to ensure it answered the needs of cancer consumers.

The next advocacy challenge is to make sure that promotion of the website is maximized - not much use spending three years on development and evaluation if it's not known about - by patients, specialists, GPs and researchers.

Most recently we wrote to all Australian Clinical Oncology Groups to alert them to the usefulness of the website and to encourage them to complete the consumer friendly fields which make it all work, based on the Australian & New Zealand Clinical Trials Register, and clinicaltrials.gov (USA for international trials open in Australia). COSA sent an email alert to its members, which we very much appreciated.

Sally has had a Letter to the Editor of the Medical Journal of Australia accepted for publication, bringing the website's existence and value to the attention of Australia's medical world. She will also make a conference presentation about the study at

the Consumers Reforming Health Conference in Melbourne in July.

Discoveries Need Dollars - campaign report

"The Australian Government has protected medical research funding in the 2011-12 budget, maintaining NHMRC funding at \$850 million. [Read NHMRC CEO Update: Outcomes of the 2011-12 Budget for the NHMRC.](#)

We are thrilled to see that the federal government has listened to the community outcry over this issue generated by the Discoveries Need Dollars campaign.

Congratulations and thanks to all of you who took action to protect medical research funding. We wouldn't be here without you."

Editor: Cancer Voices NSW formally supported this successful campaign.

Cancer Australia

The amalgamation with National Breast & Ovarian Cancer is progressing, scheduled to be completed by 30 June 2011. Several CVN members (although not under that "hat") were invited to attend the Consumer Forum in April to put forward our suggestions for the scope and operation of the new enlarged Cancer Australia. CVN continues to work productively with both organisations, through its nominees to various committees, through Cancer Voices Australia and directly

Cancer Australia, with Cancer Voices Australia, is conducting a review for a possible **National Consumer Framework**. It's aim is to provide some guidelines for stakeholder organisations which are not familiar with consumer engagement, and for those nascent consumer groups which do not yet have established processes. Kathy Smith is involved as a representative of CVA, and Sally Crossing is contributing for Consumers Health Forum to the National Reference Group which oversees the process. CVN also contributed a detailed submission to the first proposal which was circulated for comment last year. We have expressed some concern about how a National Framework would impact on the existing processes of well established cancer consumer organisations like Cancer Voices NSW, the BCAGs, and Breast Cancer Network Australia. We also noted that the exclusion of the state-based cancer consumer groups could mean loss of their greater experience of operating consumer engagement processes. We have received firm assurances that these views will be considered carefully.

Cancer Voices Australia

A Review Day was held in Melbourne on 15 April. Our nominee to the CVA Board, Kathy Smith,

attended having briefed the facilitator about our concerns, as did the nominees of the other states' Cancer Voices. We are looking forward to a report on the decisions made to underpin a more productive working relationship with our national organisation. Kathy Smith has resigned as our nominee to the CVA Board, due to concerns about some governance issues.

We understand that good progress has been made by CVA on some national issues, but regret we cannot inform our readers due to CVA's confidentiality protocols.

BITS & PIECES

Screening: Multi-million-dollar reprieve for bowel cancer screening

The first national screening program for bowel cancer has been spared an early demise, after the federal government allocated nearly \$140 million over four years to reinstate the lapsed scheme. The budget measure means the scheme can start again, but it remains unclear whether it will be expanded to achieve the scope experts say is necessary to save the maximum number of lives.

The screening program offers one-off screening to each Australian as they turn 50, 55 or 65, sending them a sample collection kit, which they then mail off for analysis. Federal Health Minister Nicola Roxon told *The Australian* the scheme was now enshrined as an ongoing program, preventing a repeat of the funding lapse.

"I agree with advocates that we need to find a way to expand the program, and our government is committed to doing that as soon as we can find a breathing space to do it," she said.

Human Gene patenting - Update

The *Patent Amendment (Human Genes and Biological Materials) Bill*, which seeks to halt the patenting of human genes and other non-invented biological materials, was introduced into the Senate in November last year with bipartisan support. If the Bill is passed into law, the kinds of patents granted to Myriad over the BRCA 1 and BRCA 2 human gene mutations linked to familial breast and ovarian cancer will be prohibited.

Unfortunately, the members of the Australian Academy of Science, don't believe the Bill should be passed. They are one of a number of scientific organisations that are opposed to the Bill. The others include The Walter & Eliza Hall Institute, the Peter MacCallum Cancer Research Institute and the Murdoch Childrens' Research Institute. They believe that the Bill will hinder their ability to patent genes. Well, they're right. It will. But these publicly funded

research institutions and the scientists they employ are supposed to be doing things for the benefit of Australians and spending millions of dollars patenting things they didn't even invent only benefits their patent attorneys and patent lawyers who are devaluing and misdirecting valuable research money that we, the taxpayers, are providing. What is even more telling is that they are on the same side as the multinational pharmaceutical and biotechnology companies which are the main culprits in all of this - these are the very companies that have been patenting human biological materials as they exist in nature. The reason why these publicly funded institutions and the scientists who are supporting them find themselves on the same side is that they are also part of the problem. The Walter & Eliza Hall is also the owner of gene patents. In fact in 2010 they made a whopping \$1.6 million in license fees from gene patents. Well, that won't go very far. More than \$55 million of its funding came from the Australian taxpayers. And by the way, how much of that \$1.6 million did they pay to their patent attorneys? And if you have any doubt about how things change look no further than Prof Ian Frazer, who having been a champion of this cause while he was chair of Cancer Council Australia, is now against the Bill. Has becoming the CEO of a \$350 million dollar organisation got anything to do with his change of heart?

What is very disturbing, however, is how the Gillard government is backing the pharmaceutical and biotechnology companies. After more than two years of a Senate Inquiry and, now a further Senate Inquiry into the Bill, neither her government nor the Rudd government have said anything to give Australian people hope that their interests will be protected.

Even the U.S. government agrees that biological materials that are merely isolated from the natural environment and which have not been changed in any material way are not capable of being patented. Isn't it about time the Australian government said the same thing?

In the meantime the test case started by Cancer Voices Australia and Mrs Yvonne D'Arcy in 2010 is slowly making its way to trial, recently re-scheduled for March 2012. Myriad first tried to derail the test case by supposedly 'donating' the BRCA patent to the Australian people. Now that that trick has failed it's U.S. based lawyers, Jones Day, have delayed the trial by not agreeing on certain elementary scientific facts such as, what is DNA? After all it can afford to throw millions at this case.

Luigi Palombi - (Australian National University)

Questions to ask your health professional

When you see a health professional such as a medical/radiation oncologist, surgeon or haematologist you may have questions and concerns. Often these are forgotten in the heat of the moment, only to be remembered later. A list of questions have been compiled to help you to get the information you want about your illness and possible treatment options. Questions to ask pamphlets for Medical/Radiation Oncology, Surgery, Haematology and Complementary Therapies can be downloaded by clicking on the links below.

You and your family can use these pamphlets to help you decide what you need to ask your health professional each time you have an appointment. Your health professional is keen to answer any questions you may have, either at the first time you see them or at future consultations. If your questions have already been answered, then these pamphlets can serve as a checklist. Remember you can ask your health professional to explain anything you are unclear about or to explain any words you are not familiar with.

Download Material

[Question List - Medical/Radiation Oncologist](#)

[Question List - Surgeon](#)

[Question List - Haematologist](#)

[Question List - Complementary Therapies](#) |

These question lists for Medical/Radiation Oncologist, Surgeon and Haematologist were developed by the Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) with funding from the Cancer Institute NSW. The question list for Complementary Therapies was produced by the Cancer Institute NSW in consultation with the Cancer Council NSW. They can also be downloaded from www.psych.usyd.edu.au/cemped

What is Cancer Voices NSW ?

Cancer Voices NSW is an independent peak advocacy organisation providing a voice for people affected by cancer in NSW. We are interested in improving all aspects of the cancer journey - focusing on detection, treatment, support and research for the benefit of the nearly 40,000 people diagnosed with cancer each year in our state, and the hundreds of thousands whose lives are affected by our disease. Many members belong to cancer advocacy and support groups. Cancer Voices NSW is an umbrella coalition for their combined interests and activities. We also welcome individuals, carers, and interested cancer health professionals as associate members.

Cancer Voices NSW Objectives

- *To reduce the impact of cancer on the community, in terms of lives affected and lives lost.*
- *To promote a balanced public awareness of cancer.*
- *To define the issues that are important to cancer consumers and advocate measures to address them.*
- *To work towards ensuring access to the highest quality treatment and support services for people with cancer, regardless of their geographical location, social or economic status, ethnicity or stage of disease.*
- *To encourage, and to provide a facility for, those with experience of cancer to contribute to all levels of decision making about the disease.*
- *To influence the direction of research into the causes, and prevention of cancer, optimal treatments and support for those with the disease.*
- *To provide a forum for people affected by cancer to share experiences and information.*

CVN stars in "Achievements in Cancer Services and Education, 2010"

Bev Noble, CVN Executive Committee member and experienced CVN Rep, features on the front cover of this new Cancer Institute NSW (CINSW) Report, and has a full page photo and story on pages 40-41. The next two pages record the working relationship between CINSW and Cancer Voices NSW. Cancer Voices NSW thanks the Cancer Institute for this recognition and looks forward to many more years of offering the informed cancer consumer view.

CONTACT CVN

Contact CVN either by visiting the website

www.cancervoices.org.au

Or by email to info@cancervoices.org.au or by post to PO 5016 Greenwich NSW 2065; Tel: 02 9436 1755

THANKS

Cancer Voices NSW thanks the NSW Cancer Council for its assistance in printing and posting our newsletter. It is greatly appreciated

