

Message to Members: Welcome to the First CVN Newsletter 2012

As some of you may be aware, I was elected as Chair of CVN at the AGM held on the 8 Feb, 2012. I am honoured by the trust placed in me by my fellow members, and guarantee that I will work to the best of my ability to ensure that CVN remains the successful organisation that Sally Crossing has made it over the last 8 years.



Fortunately, Sally agreed to remain on the Committee as Deputy Chair, so that corporate memory remains to assist us in our endeavours. Sally will continue to lead projects that she has spearheaded for some time. In order for me to follow successfully in Sally's 'big' footsteps, I will draw on the experience and assistance of the Executive Committee and the membership at large. This membership includes people with many skills and strengths, and I would like harness some of these in order to continue advocating for the best possible outcomes to improve the experiences of cancer patients, their families and carers. Please contact us if you would like to work more closely

with the Executive Team, or if you would like to raise awareness of any issues in your local area. If you want to advocate for change yourself, or would like us to fight for you, please let us know. We can't do anything until you tell us!

I would particularly like to hear rural and regional member's opinions of new cancer centres under construction. We are told how these facilities are going to see the tyrannies of - lack of access to treatment, long waiting times for appointments with visiting oncologists etc, become things of the past. We would like to think that this will be so, but what do you think? What areas do you feel will still be in need of attention when these cancer centres are open for business? Please send your opinions, to enable us to track shifting areas of need.

I hope you enjoy reading what we have been up to over the last few months. Please feel free to write and tell us what is happening on the cancer scene in your area. In conclusion, I wish all members a happy and successful year on behalf of us all on your CVN Executive Committee.

Best Wishes, **Kathy Smith, Chair**

Message from Deputy Chair

I am delighted to be handing over the reins to Kathy this year, having worked closely with her over the last few. This reflects our interest in positive succession planning, to ensure that Cancer Voices NSW remains strong and active. It is a good time for a change of leadership. We are in a good place, ready to build on eleven years of successful cancer consumer advocacy.

I feel very confident that Kathy will do an excellent job, and have offered to stay on as her Deputy to ensure corporate memory, and to help in those policy areas that I have worked on most closely. I will also continue to collate and edit our newsletters. You may know that I have taken on the job of Chairing Health Consumers NSW (HCNSW), the newish state peak organisation which provides a voice for NSW health consumers at state level, a bit like Cancer Voices but generic in scope and advocacy interests. I will briefly report on HCNSW's work where it is of interest to people affected by cancer.

Kathy has served on the CVN Executive Committee since 2008. Readers of this newsletter will know that she proved her mettle through leading the campaign for public radiotherapy services on the Central Coast, and subsequent full new cancer centre, as announced by the then Prime Minister in April 2010, and due for completion this year. Kathy (assisted by Barb Galvin), has taken over the roles formally performed by Sally H ie Membership Database, Consumer Reps Program placements, and Newsletter management. This is all fine, BUT we do need new helpers to share the load. Please let us know if you have any experience and interests which could assist

Cancer Voices to do more of the good work it does for people affected by cancer.

Sally Crossing, AM

**Learn About Advocacy and Consumer Representation?
Consumer Advocacy Training (CAT) Courses 2012
16th and 17th March 2012 – Grafton & 23rd and 24th June – Sydney**

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

Cancer Voices NSW recommend 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 by cancer, should sign up for a place in this excellent introductory course.

Consumer Training in Research

Training (1-2 days) will be held in mid-August, 2012
Please send Expressions of Interest to
Cancer Council NSW at research@nswcc.org.au
CVN's June Newsletter with give full details, but apply early to ensure a place!

Awards for Excellence in Cancer Consumer Advocacy 2013

Cancer Voices NSW invites you to nominate a cancer consumer who you believe has served the interests of people affected by cancer very well over several years.
Please send nominations to Cancer Voices NSW
info@cancervoices.org.au
including the name of the nominee, reasons for your nomination, and your contact details
Closing Date : 1 December, 2012

New Cancer Services Consumer Network

Expressions of Interest are invited to join two new CVN Networks
Rural and Remote Cancer Services Network, and
Metro Cancer Services Network

These recognise that rural and metro cancer services face different issues and needs
Let us know if you are interested in participating in two-monthly teleconference sessions by
Emailing: info@cancervoices.org.au

**Important New Website Information for People
Affected by Cancer**

Australian Cancer Trials Online
www.australiancancertrials.gov.au
Cancer Specialists Directory
www.cancerdirectory.org.au
CA's National Framework for Consumer Engagement
www.canceraustralia.gov.au

THANKS

**Cancer Voices NSW greatly appreciates the
assistance given by Cancer Council NSW in printing
& posting Cancer Voices Newsletters.
Contact CVN: PO Box 5016 Greenwich 2065
info@cancervoices.org.au**

CVN COMMITTEE NEWS

CVN Committee Business: CVN held its AGM on 8 February at the Cancer Institute NSW. Sally Crossing tabled and presented the 2011 Annual Report, which is reprinted in this newsletter. Our healthy financial statements were lodged with NSW Fair Trading.

The CVN Executive Committee for 2012 is:

Chair: Kathy Smith

Deputy Chair: Sally Crossing

Minutes Secretary: Jane Barrett

Committee: Tony Maxwell, Bev Noble, Elisabeth Kochman, Peter Brown, Jane Barrett, & Roberta Higginson.

Treasurer: Co-opted accountant member, Sandra O'Sullivan, kindly agreed to continue in this role.

CVN members interested in being a part of the CVN Committee are welcome to join us for a meeting or two to see how it works. New ideas and skills welcome!

Membership: There are currently 86 group (voting) memberships and 390 individual members.

Award for Excellence in Cancer Consumer Advocacy : Following official business, we presented the inaugural 'Award for Excellence in Cancer Consumer Advocacy' to Sally Hodgkinson, received by her brother, Stephen Hodgkinson.



Meeting with CINSW: Holding our AGM at the Cancer Institute NSW (CINSW) gave us the opportunity to meet with senior CINSW staff, and discuss their programs of special interest to people affected by cancer, and our working relationships.

- *David Currow*, CEO & Chief Cancer Officer,
- *Sanchia Aranda*, Dir, Cancer Services & Information Div,
- *Mary Haines*, Dir, Strategic Research Investment Division, &

- *Anton Bergheim*, Man, NSW Cancer Registry Strategy.

We look forward to continuing our close working relationship with the CINSW, by providing the consumer perspective for their work in policy and programs of interest to our members. We are pleased to report that the CINSW decided, after some years of advocacy on our part, to include consumer perspectives on their research review panels, and other area of research. We are in discussion with the new Director, Strategic Research Investment Division, about this and will advise you regarding new opportunities.

CVN CONSUMER REPS IN ACTION

“Nothing about us without us!”

Presentation of AWARD for Excellence in Cancer Consumer Advocacy

This year CVN established this award to honour those amongst us whose efforts make a real difference for people affected by cancer.

In 2010, we published the record of our first ten years of successful cancer consumer advocacy – **A Decade of Success: Cancer Voices NSW, 2000-2010**. One of its most rewarding outcomes was the number of people in the cancer care and research world who went on record to acknowledge the value of our “voices” being heard in an informed and organised way.

The obvious next step was to annually publicly honour an individual who demonstrated excellence in his or her cancer consumer advocacy work.

We are delighted to announce the inaugural AWARD to **Sally Hodgkinson with** no contest. Sadly, Sally died of her cancer late 2011. Sally's work for CVN was both behind the scenes as Hon Sec, Database Manager, Consumer Reps Program Manager, a major contributor to policy development on issues raised by our members, AND in the thick of things via an array of important consumer rep positions. Sally had a particular interest in the direction of cancer research, and consumer involvement therein, as well as issues for country people. She was the complete consumer advocate and is remembered for her hugely useful contributions as well as her own 'no mucking about' attitude.

Nominations are invited for the 2013 Award for Excellence in Consumer Advocacy for presentation at our AGM, Feb 2013 Please send nominations with info to:

Consumer Reps Program

Report

Overall Consumer Representation: We service 162 committees of different types. 75 nominated individual consumers sit on these committees for 52 different organisations. (This does not include the reviewing activities for organisations such as the Cancer Council NSW, NBOCC etc.)

Research Projects: There are 68 individual research projects within 21 organisations for which CVN provides consumer input.

Consumer Advocacy Training

Welcome to Graduates of the 2012 CVN

CAT Courses: We are here to help you find the kind of representations, advocacy or other activity that most interests you. The quarterly newsletters will keep you informed of our activities, and are a vehicle for you to tell others about yours. Please let us know of issues you would like to raise with us, so we may include them for advocacy and policy development. We have added you to the database of trained consumer reps and will offer you a role when suitable requests are made to us, based on the information you provided about your interests and experience.

CAT Courses for 2012

16/17 March (Grafton) and 23 /24 June

(Sydney) :

CVN recommends that anyone interested in taking part, speaking up, writing about their ideas or concerns, being a CVN Consumer Representative by signing up for Consumer Advocacy Training.

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 as 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

New Cancer Services Networks

CVN decided to establish two working groups to replace our old 'Area / District Cancer Services' group, recognising that metro and rural cancer services face different issues and needs. We now call for expressions of interest from members to join either the Rural & Remote Cancer Services Network, or the Metro Cancer Services Network by contacting info@cancervoices.org.au.

Consumer Involvement in Research (CIR) Program

CIR Requests for informed consumers: We have had a surge in requests for informed, preferably trained consumers who can contribute the consumer perspective to research grant applications. Most grants now require this, another successful CVN initiative of some years ago. While we do our best to meet the demand, we are aware that it will become more than our resources can cope with. We also know that researchers now need this service across Australia, not just in NSW. With this in mind we are exploring various avenues for expanding our service, including using it as a template for a well-funded national program, possibly beyond cancer itself. Feelers have been extended to a range of possible partners to join in applying for a Cancer Australia Grant. We will keep you informed of progress.

Consumer Research Training 2012:

CVN confirms that Cancer Council NSW will hold a training session for people interested in assisting cancer researchers and funders by providing the consumer perspective during August, 2012. We will provide further information in our June Newsletter. CVN is very keen for a new batch of graduates, as researchers are increasingly asking for informed consumer nominees to advise them on research projects, at all stages. Please forward 'Expressions of Interest' to Sam Thorp by telephone: 02 9334-1445, or via email to research@nswcc.org.au.

CVN ADVOCACY UPDATES

Radiotherapy – Out of Pocket Costs:

Our current advocacy focus regarding radiotherapy is large gap payments, often unexpected, which private patients must pay for radiotherapy treatment. This is because private health insurance does not cover any services for which there is a Medicare rebate, and if they are outpatient services. We are partnering with two pro bono advisor friends of CVN, and Cancer Council NSW, to look into the options to improve this major financial burden for those who find themselves faced with a bill for several thousands of dollars.

Palliative Care Campaign – Next Steps 2012:

CVN's Dep. Chair, Sally Crossing, has been appointed to the Palliative Care Expert Advisory Group as the Health Consumers NSW nominee. Yvonne McMaster, CVN member, is another consumer rep, so we feel confident that our voice will be well heard. The PCEAG is working with the NSW Ministry of Health MP, to progress the commitment of the Minister for Health, the Hon Jillian Skinner, to examine how to make improvements to palliative care services in NSW. An interim report has been finalised, and the final version should be available by June newsletter time. We have continued to push for some real evidence on which to base real changes. Palliative Care appears to have become the poor cousin within health services, which is a major oversight by planners, as the population ages and more people need it. There are economic arguments to reform the system as well. Currently far too many people end up in acute care hospital beds which are up to ten times as costly as palliative care beds, and of course even more than proper hospice or home-based care.

Talking to Young Doctors about Palliative Care:

It was suggested by a CVN member that we investigate developing a session with undergraduate doctors about the importance of palliative care, and its co-ordination from the patient perspective. This could be modelled on the successful "BabyDocs" program run annually for many years by the Breast Cancer Action Group NSW and USyd Medical School, a CVN founding member. Your views?

CVN Submission to Senate Inquiry - Palliative Care in Australia: CVN made a

submission to the Senate Inquiry into Palliative Care in Australia, referred to the Senate Community Affairs Committees on 23 Nov, 2011 for inquiry and report. Our submission will appear on the Senate's website with public access. The Inquiry is very timely for us to get the message across to an audience beyond NSW. We understand from sister Cancer Voices SA that the issues are, not surprisingly, very similar.

Cancer Statistics Presented by ABS – A Win:

Following our approach, the Australian Bureau of Statistics expressed interest in establishing a new table which will aggregate cancer deaths, so that statistics show cancer as the main cause of death in Australia, a powerful fact for decision-makers. This advocacy has been on our plate since 2011, when we realised that the media was unaware of this fact, due to the manner in which the statistics are currently presented. We have been advised by the ABS that the latest Causes of Death Stats due on 20 March (Chapters 2/3) will contain tables which give cancer its due weight. (Full details – June Newsletter).

Cancer Services Directory:

www.cancerdirectory.com.au CVN participated in the development and evaluation of this new website, and entered our own publication **A Decade of Success: Cancer Voices 2000-2010** onto the electronic register.

IPTAAS – Isolated Patients Travel &

Accommodation Scheme: CVN contributed to an all-day NSW meeting on 6 Dec, which sought to simplify the complex IPTAAS forms. We are confident that this will now occur, and await the report of outcomes and decisions. Financial assistance through IPTAAS received additional funding from the new NSW Government, effective from 1 Jan.

Cancer of Unknown Primary (CUP) News

New Cup Action Website : CUP Action works for people affected by cancer of the unknown primary. One of CVN's roles is to help smaller or rarer cancers establish advocacy and/or support groups and to gain a profile. We are delighted to add this website to the family list ! It is a good model for other lesser known cancers. Visit www.actiononunknownprimary.org

Dying with Dignity: Supported by UK

Commission: The UK Commission on Assisted Dying released its report on 5 Jan, 2012, reported by The Lancet. Thanks to Yvonne McMaster, CVN member, for passing this on to us. It argues that it is possible to 'devise a legal framework that sets out strictly defined circumstances in which terminally ill people could be assisted to die', provided that up front safeguards are in place.

CVN members have continued support for the NSW Greens Bill to legalise voluntary euthanasia. We attended a public meeting on this subject at NSW Parliament on 15 Nov, 2011, as did many prominent Australians. It is recognised that while some religious doctrines prevent consideration of some of the issues, open debate and access to information is the right of those not so constrained. CVN recognises that a small proportion of those who die of their cancers, may find themselves in the insidious position of having no control over the manner of their dying, and that the lead-up to death may become insufferable. We want to keep informed, and support all efforts to ensure that dying with dignity is available to us.

Position Statements

This useful information about major issues for people affected by cancer is updated annually and new ones are under consideration.

See www.cancervoices.org.au.

Let us know if you have an issue that needs attention and which you think would be a suitable topic for a CVN Position Statement. Published in this newsletter and later on the website, they are useful for stakeholders and our own members to see the current thinking about specific issues which concern or interest people affected by cancer.

The Voices being heard

The activities below are listed to give an idea of CVN's various involvements during the quarter:

CVN's nominated consumer reps attended a number of regular committees and research project meetings. Let us know if you would like these to be included.

Submissions:

- Cancer Service Networks National (CanNET) Program: national evaluation (Jan)
- Palliative Care NSW's Policy Discussion Paper
- Australian Senate Inquiry: Palliative Care in Australia

Major Meetings:

- IPTAAS Feedback Forum: Ministry of Health, 6 Dec
- Consumer Engagement Workshop, COSA, 9 Dec
- Cancer Council Australia - CVA, 3 Jan
- Macquarie Uni Hospital, 4 Jan
- Cancer Directory Advisory Committee, CCNSW, 1 Feb & 8 Mar
- Consumer Engagement, Steering Cttee, COSA, 2 Feb
- Palliative Care Expert Advisory Group, 17 Jan, 7 Feb, 21 Feb
- Gaps in Colorectal Research, USyd, 9 Feb
- Clinical Mgt Cttee, CINSW, 15 Feb
- State Cancer Voices – CVA, CCA, 16 March

Events:

- Complementary Medicines Seminar CCNSW, 1 Mar
- Patenting of Genes Symposium, USyd, 13 Feb
- Australian Federal Court; Myriad Genetics / Patent on human genes

Publications / Media:

(Editor's Note: CVN has a positive policy about participating in studies for which we have advocated, and for being included as a co-author. This helps get our profile into the so-called 'black literature', which is highly regarded and cited by cancer world stakeholders. CVN members are encouraged to advise us of publications of which they are an author or co-author, particularly those in peer reviewed journals. The list is at about 18, and growing. The following were published in the first quarter, in which Sally Crossing was a co-author.

- *Workforce Shortages in Medical Oncology: a Looming Threat to Quality Care*, MJA 196 (1) – 16 Jan, (Authors Koczwara, Barton, Walpole, Grimison, Blinman, Crossing, Francis).
- *The Shortage of Medical Oncologists: the Australian Medical Oncologist Workforce Study*, MJA 196 (1) – 16 Jan, 2012. (Authors Blinman, Grimison, Barton, Crossing, Walpole, Wong, Francis, Koczwara).
- *Impact of a Cancer Clinical Trials Web site on Discussions About Trial Participation: A Cluster Randomized Trial* (Authors R. F. Dear; A. L. Barratt; L. M. Askie; P. N. Butow; K. McGeechan; S. Crossing; D. C. Currow; M. H. N. Tattersall). *Annals of Oncology* 2012; doi: 10.1093/annonc/mdr585

WHAT'S HAPPENING AT STATE LEVEL?

Isolated Patients Travel and Accommodation Assistance Scheme

(IPTAAS): "The NSW Government is delivering a boost of \$28 million over four years to the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS). This program provides financial assistance with travel and accommodation costs for people (and eligible escorts), who need to travel long distances for specialist medical treatment not available locally.

The funding boost will increase the number of people who can access the scheme and provide greater financial assistance to patients. Previously patients travelling a distance of at least 100km each way were eligible. The recent changes announced by the Minister for Health mean that from 1st January 2012 any patient travelling a cumulative distance of at least 200km per week to access their nearest treating specialist is also eligible. This will significantly increase the number of people who can benefit from the Scheme, particularly those that need regular specialist treatment for a chronic disease. Eligible patients will also receive a massive 30 per cent boost in accommodation subsidies and a 25 per cent boost in petrol subsidies. The changes to IPTAAS, effective from 1st January 2012 are:

- Increase in fuel subsidy from 15 to 19 cents/ km,
- Private accommodation subsidy increase from \$30 per week to \$140 per week and the previous one-week exclusion period discontinued,
- Increase in the commercial accommodation subsidy from \$33 to \$43 per night for a single room, and \$46 to \$60 per night for a double room,
- The \$40 co-contribution levied on each claim made by non-pensioners/ non-health care card holders will be capped once a patient's IPTAAS subsidies reach \$1,000 within a one year period, &
- Claims are to be processed within 30 days of their receipt. Previously, the time limit for processing claims was 45 days."

To apply for financial assistance, eligible patients must complete an application form, which should also be signed by the referring practitioner and treating specialist. Information about the Scheme can be found by visiting NSW Health website at: <http://www.health.nsw.gov.au/living/transport/iptaas.html>

(Editor's Note: CVN members will notice the fruits of previous years labours in this announcement, an election promise by the now NSW Govt. We welcomed improvements at the time, but note that two outstanding issues are yet to be addressed ie inclusion of participating clinical trials for IPTAAS, assistance at present trials are not regarded as treatment! And, an overhaul of the complex forms, eliminating countersigning processes by various

doctors. We have ensured that the Ministry of Health is aware of the need to resolve both issues.)

News from Health Consumers NSW:

Health Consumers NSW (HCNSW) is the new peak health consumer organisation which provides an independent voice for people using health services in NSW. Cancer Voices NSW is a founding member. HCNSW has released its full package, including training content, relating to **Policy & Practice for Health Consumer Representation** through HCNSW. This package has been prepared to inform stakeholders and consumers of roles, expectations and processes, and is based on current best practice. We think it will be useful for many organisations wishing to engage with NSW health consumers.

CVN will be co-hosting a **Leadership Workshop** (Health Consumer and Community Leaders' Workshop – empowering consumers and the community to make a difference in health) with the Consumers Health Forum of Australia on 7th & 8th March in Sydney. This follows a successful national launch in Canberra last year, opened by Minister Roxon. Attendees will be Chairs and CEOs of Local Health Districts (LHDs) and Medicare Local Boards, and the Consumer Board members.

Health Consumers NSW will be holding a **Chronic Disease Consumer Forum** on 13 March, to focus on and inform our **Chronic Disease Consumer Network's** work and advise NSW Ministry of Health of consumer perspectives. There has been extremely encouraging interest from our members.

We have also established a **Palliative Care Consumer Network**, and have representation on the Ministry of Health's Palliative Care Expert Advisory Group which will report to the Minister regarding her commitments re state-wide improvement in palliative care services in August 2011, following the petition (24,000) raised with CVN and subsequent Parliamentary Debate.

To Contact HCNSW: (T) 02 8875-4622
(E) secretariat@hcnsw.org.au
(W) www.hcnsw.org.au

Cancer Council NSW

Enrich Your Life! :

Registrations are now open (until April, 2012) for all cancer survivors, carers, partners and family members to join the ENRICH Program. ENRICH will help make lifelong positive changes to your **Exercise and Nutrition Routine to Improve Cancer Health!** This program is being run as part of a Research Study in collaboration with the University of Newcastle. Programs will be held in Casula, Wahroonga and Penrith during May and Oct, 2012. For more info please call Gabrielle Asprey, Project Coordinator on 1300 360 541 or email: gabriellea@nswcc.org.au

Living Well After Cancer Program:

Cancer Council NSW runs a popular program for cancer survivors, carers, family and friends called **Living Well after Cancer**. It offers practical information, discussion and ideas about how to adjust to a raft of changes following cancer treatment. The success of the program lies in its facilitation, with the volunteer facilitators being cancer survivors or carers, who are highly skilled in presenting workshops. Programs are free and open to all cancer survivors, carers, family, and friends. Anyone who is affected by survivorship issues can attend to connect with others who have been through a similar experience, and to share tips, ideas and activities for adjusting to life after cancer. Programs are advertised at www.cancercouncil.com.au. Call **1300 200 558** for more information. about metropolitan and regional locations.

Cancer Institute NSW (CINSW) :

CINSW marked the eve of World Cancer Day, 4 Feb, with the launch of its Cancer Referral Website, **Canrefer**, to help general practitioners and cancer patients search for healthcare teams specialising in the treatment and care of specific cancers across NSW. Launched by the NSW Minister for Health & Minister for Medical Research, Jillian Skinner, **Canrefer** is a comprehensive database of all cancer specialists operating within a multidisciplinary team across New South Wales and the ACT. It also includes practical information on individual facilities, such as maps, opening hours, and parking costs, and if the service is offered by public or private providers.

*(Editor's NOTE: A specialist directory for NSW has been an advocacy thrust for CVN since we acknowledged the value of founding member Breast Cancer Action Group NSW's **Directory of Breast Cancer Specialists NSW**, first published in 2001. We took the concept to Cancer Australia in its very early days, then to CanNET at national level. It was*

agreed that directories were an essential part of the information package needed by people with cancer and their referring doctors, but for some time the provision of actual contact details seemed impossible. Persistence paid, and in the end the Cancer Institute was able to develop an excellent website which enables just that, and a lot more. CVN worked closely with CINSW on this project throughout its course. We invite members to check it out and provide us with feedback about its use for your purposes).

WHAT'S HAPPENING NATIONALLY?

Consumer Engagement in Cancer Research :

CVN is working on the Steering Committee set up by the Clinical Oncology Society of Australia (COSA) to develop a *Consumer Engagement Policy* for its Clinical Oncology Groups (a Cancer Australia Grant supports this excellent project). Part of this includes a consumer research training module, of great interest to us, with our 7 years of experience through a joint program with the Cancer Council NSW. A Workshop was held on 9 Dec, attended by consumers and researchers, which produced a rich collection of ideas and issues which will inform the project's direction, and our own.

Towards a National Cancer Research Plan:

The Cancer Research Leadership Forum (CRLF) has just released its White Paper '**Towards a National Cancer Research Plan**', and is seeking community and other stakeholder responses. The paper calls for development of an all-embracing National Cancer Research Plan for Australia to coordinate investment in research, improve funding efficiency, and accelerate progress to benefit people with cancer.

The CRLF was established in 2009 to foster collaboration between national community-supported cancer organisations that fund cancer researchers and their work in Australia. It currently includes the *National Breast Cancer Foundation, Bowel Cancer Australia, Cancer Australia, Cancer Council Australia, Cure Cancer Australia Foundation, Leukaemia Foundation, Melanoma Institute Australia, and Prostate Cancer Foundation of Australia.*

To provide feedback on the issues and questions presented in the [paper](#), or to make recommendations about the actions required to improve cancer research planning and coordination in Australia, please email CRLF at crlf@nbcf.org.au or by mail at The Cancer Research Leadership Forum C/- National Breast Cancer Foundation, GPO Box 4126 , Sydney NSW 2001. **Submissions close on 1 May 2012.** CVN will be making a submission. A national summit will be held following the consultation period in September, and we plan to participate in this. CVN has worked closely with some, but not all of these research funders, some of whom we understand have yet to include the informed consumer view in their grant processes.

Website : www.nbcf.org.au

Email: crlf@nbcf.org.au

Comments & Submission Close mid-

We understand that another **National Cancer Research Plan** is being put together, but as yet we have no further information. The development of such cancer plans has been on the advocacy agenda of CVN for many years (See Position Statements), and we are keen to contribute our extensive knowledge and experience from the consumer perspective.

Cancer Australia

Supporting People with a Cancer Grant Initiative:

In late 2011, CVN, together with a national and experienced team, attempted to apply for a CA Grant to develop a training framework to assist implementation of the principles of the **National Framework for Consumer Engagement**. However, we heard about it too late, and a request for an extension of time was refused, to our disappointment. We believe that our consortium was the best qualified to undertake this work, due to combined long experience and expertise. Subsequently Cancer Australia agreed to notify CVN of all new grants offered.

It is with pleasure that I present my last Annual Report for CVN. I think it is time for a change after 8 years as Chair. I feel very confident that our succession planning will ensure that things will continue smoothly and upwards. I would like to continue to contribute corporate memory as an Executive Committee member and be active in policy and advocacy work – my own biggest interests.

Since 2000, our purpose had been to collect, and to act on, the needs and interests of people affected by cancer in our state and beyond. Despite considerable advances in treatment and care, cancer incidence continues to grow, and our task remains a large and important one. We pride ourselves on being directly informed by our members, focussing on the areas of diagnosis, information, treatment, research, support and care.

A major highlight this year was the publication of **A Decade of Success: Cancer Voices NSW 2000-2010** whose 48 pages record our growth and achievements. I am proud of both, and of the record itself, particularly as many consumer organisations leave no record of their work. We are very conscious of the need to provide hard evidence of our value and effectiveness, and it does this. Distribution to all members and stakeholders was a major outcome for 2011, and the booklet will continue to be an important profiling tool for CVN and the Australian cancer consumer movement.

Another 2011 highlight was a hugely successful advocacy campaign - the **Cancer Voices NSW Palliative Care Campaign 2011** based on our members' expressed concerns. We received over 23,000 signatures to a petition, subsequently tabled in Parliament and debated with bipartisan support and briefings from us, on 10 August. Palliative Care funding was restored in Northern Sydney and CVN is now an integral partner in ensuring the Minister for Health's commitments for improving services statewide are actualised.

A further win was the arrival of an electronic **Cancer Specialist Referral Directory** (at www.canrefer.org.au), something for which we have strongly advocated at both national and state levels. We collaborated with Cancer Institute NSW which developed the Canrefer Directory under the CanNET program. It will be of huge value to cancer patients and their referring doctors. Main advocacy issues for CVN in 2011 were:

- better access to radiotherapy, with a major start on the Central Coast,

- optimal workforce levels of cancer specialists, especially in medical oncology and palliative care,
- cancer specialist directories and Treatment & Care Plans,
- adequate public funding of, and access to, the full range of palliative care services,
- consumer involvement, training and placement of representatives for advocacy and research,
- encouraging the progress of personalised medicine through genomics research,
- further IPTAAS reform – new NSW Government announced improvements,
- aggregated cancer statistics to be provided by ABS,
- problems around private health insurance cover for cancer patients,
- promoting the Australian cancer trials website www.australiancancertrials.gov.au,
- developing and promoting a Consumers' 12 Point Cancer Research Plan, and
- offering assistance to rarer or less known cancer groups for advocacy and research efforts.

Voices being heard: Nothing about us without us!

CVN's match-making service for stakeholders seeking the consumer perspective continued. As at Dec, 2011, we provided nominees to a total of 155 committees of different types. 74 individual consumers sit on these committees for 52 different organisations.

We also reviewed texts to be published by the Cancer Council NSW. There are 68 individual research projects within 21 organisations for which CVN provides consumer input. Representative positions are with all organisations which make decisions about people affected by cancer eg the Cancer Institute NSW, the Cancer Council NSW, District Cancer Services, Cancer Australia, University of Sydney, University of NSW, and some individual hospitals and research organisations. This year we developed a model **Memorandum of Understanding with the Garvan Institute.**

Five Consumer **Advocacy Training (CAT)** courses were held with CCNSW in Sydney, and their graduates invited to join Cancer Voices. No Consumer Involvement in Research (CIR) training course was held in 2011 which placed a strain on our ability to provide trained nominees to cancer researcher projects. Our nominees also reviewed proposals submitted to research funding organisations including Cancer Australia, Cancer Council NSW, the National Breast Cancer Foundation, Sydney Cancer Network (USyd), UNSW, and the Garvan Institute. We participated

actively in the development of Cancer Australia's National Framework for Consumer involvement in Cancer Control and in COSA's project Enhancing Consumer Engagement in Research.

DCS Program

The District (previously Area) Cancer Services Reps Program continued its work, but was constrained due to uncertainties around the new cancer services arrangements in the Local Health Districts.

The Written Word

Written submissions to major cancer-related inquiries, and on request, remain an important avenue for the 'voice' and a number were made during the year. 27 Position Statements are now posted on our website as public documents, with 4 additions in 2011. 4 quarterly 8-12 page newsletters were published in hard copy and posted on the website where they are searchable. Newsletters were edited by Sally Crossing, formatted by Barb Galvin & Kathy Smith, proof-read by Elisabeth Kochman, printed and mailed by the Cancer Council NSW. We receive good feedback about their content and quality. We have continued our reputation-enhancing policy of participating as co-authors in peer reviewed articles reporting various research studies of particular interest to our constituency.

Speaking Out

We attended conferences, seminars and workshops to keep up-to-date, and to put the cancer consumer view. Invited presentations were made at a number of these, and recorded in each newsletter.

Electronic Communications

www.cancervoices.org.au . CVN's Wikimedia based website continues to connect interested people with CVN with instant updates, newsletters, membership applications and the vital 'match-making' service for requests for consumer representatives.

Media Impact

CVN always responds to requests to provide the consumer view on issues as they arise in the media. Several of us have been interviewed for various books, magazines and studies during 2011.

Profiling

CVN mailed around 1000 copies of **A Decade of Success** to members, cancer service providers, stakeholders, the media and other interested organisations, and will continue to use it as a promotional resource.

Organisational

As at Dec, 2011, Cancer Voices NSW members numbered 86 cancer support and advocacy groups (voting members), 263 individuals and 125 Associate and 'for information' members. 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.

The 2011 Executive Committee met regularly at the CBD offices of UBS Investment Bank (also pro bono), and out of session as necessary. Members this year were Sally Hodgkinson (Hon Sec), Elisabeth Kochman, Tony Maxwell, Beverley Noble, Kathy Smith, Jane Barrett, Peter Brown, Yvonne , McMaster, Sandra O'Sullivan (co-opted Treasurer) and Sally Crossing (Chair).

The Bigger Picture

CVN became a founding member of Health Consumers NSW, and actively participated as a member of the Consumers Health Forum of Australia and of Cancer Voices Australia.

Vale Sally Hodgkinson

We were very saddened by the death of Sally Hodgkinson on 28 Sept, and will remember her huge contribution to CVN by initiating an **Award for Excellence in Cancer Consumer Advocacy**. Sally herself is its first recipient, albeit posthumously.

Financial

We were delighted to receive Gift Deductible Recipient Status from the ATO this year, which means that donations are now tax deductible. We received valued pro bono support from the Cancer Council NSW (newsletter printing and mailing and of teleconference assistance), and the Macquarie Uni Hospital kindly sponsored the design and printing of the **Decade of Success** publication. The Treasurer's Report for 2011 is presented separately.

Reflections and Thanks

2011 was another successful year for CVN. Our voice is respected, sought out and noted where decision-making impacts people affected by cancer. Special thanks go to the 2011 Cancer Voices NSW Executive Committee and our very effective and informed consumer representatives. And of course, thanks as always to our stakeholders and partners for their support, encouragement, inclusivity and respect.

**Sally Crossing AM,
Chair**

BITS & PIECES:

Cancer Council NSW

(Editor: CVN is always invited to comment on new CCNSW information booklets and on revisions of previous ones. We appreciate the opportunity to provide the informed consumer view to these very useful booklets, available from the Cancer Council, from their shops (free) and from their HUBS at NSW Cancer Centres)

New titles:

- Cancer, Work & You
- Understanding Breast Prostheses & Reconstruction
- How Can I Help? Supporting Someone with Cancer (Brochure)
- Understanding Cancer of Unknown Primary

Revisions:

- Understanding Skin Cancer
- Understanding Bowel Cancer
- Understanding Thyroid Cancer
- Overcoming Cancer Pain
- Understanding Chronic Leukaemia Cancer
- Understanding Prostate Cancer
- Understanding Cervical Cancer
- Massage and Cancer
- Understanding Brain Tumours
- Understanding Vulva and Vagina Cancers
- Understanding Breast Cancer
- Cancer in the School Community
- Caring for Someone with Cancer
- Understanding Non-Hodgkin Lymphoma

Cancer of the Unknown Primary
The Council Council NSW has a new look to its website. There is information about cancer of unknown primary plus research they are undertaking into the information and support needs of those affected by CUP.

<http://www.cancercouncil.com.au/cancer-of-unknown-primary-cup/>

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- So suck in each day as it comes and enjoy the flavours - they are great.
- Live with grace rather than die with the cancer.

(Editor: Thanks to Tony Maxwell for passing this on to the Newsletter – food for thought!)

GRACE : Coming to Terms with Your Own Mortality

Website Information News Forms

Consumer Reps Requests: To request a consumer rep for your organisation or group, please complete the form online (see note below)

Membership: To apply for membership of Cancer Voices, either as an organisation or individual member, please download the membership form.

Other Features :

All CVN newsletters are held on our website and are searchable

28 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

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 or decision making about the disease,**
- **To influence the direction of research into the causes, and prevention of cancer, optimal treatments and support of those with the disease, and**
- **To provide a forum for people affected by cancer to share experiences and information.**

What is Cancer Voices NSW?

Cancer Voices provides the independent voice of people affected by cancer. It is the peak coalition for cancer support and advocacy groups in NSW, 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.

Join Cancer Voices NSW

See www.cancervoices.org.au

For an online form and pay no membership fees

Be in the loop about our advocacy on behalf of people affected by cancer, and contribute to improving things with us.