



## Message to Members

**A Decade of Success: Cancer Voices NSW 2000-2010<sup>9</sup>** : Around 1,000 copies have been mailed to all CVN members and interested others, and to NSW Cancer Support Groups and Palliative Care Centres. This milestone publication has been enthusiastically received, and is a very useful profile tool for CVN. Telling people who we are, what we do and why, and what we have achieved in our first decade, has substantially added to the history and analysis of the cancer consumer advocacy movement.

**AGM and Get-together at Cancer Institute NSW - 8<sup>th</sup> February, 2012** : We hope to see you at this opportunity to learn more about CVN from our view point, and more broadly. The formal AGM will be short, then we can meet and greet each other, enjoy the update on the CINSW, and discuss cancer consumer needs and issues.

**Vale Sally Hodgkinson:** We are deeply saddened by the death of our dear friend and colleague, Sally Hodgkinson on 28<sup>th</sup> September. Many of you will have known "Sally H" through her pivotal roles in the management of CVN's major processes – Membership, Consumer Reps Program, and as Hon Secretary. We sorely miss her and her huge contribution to CVN, and other stakeholder organisations on which she served as consumer rep. (See more about Sally at pp 11-12).

**Highlights this Quarter:** For details of follow-ups on the Government's 10<sup>th</sup> August commitments concerning Access to Palliative Care, IPTAAS Improvements, Consumer Engagement Strategies, and the CanRefer Directory – see inside.

On 5<sup>th</sup> October, the first sods were turned to officially mark the beginning of construction of the Central Coast Cancer Centre. As readers will know, this Cancer Centre is the result of the long fought campaign by CVN for public radiotherapy facilities on the Central Coast. (See full story, p.4).



### Central Coast Cancer Centre Underway at Last !

(From Left to Right)

Lyn Smith (Wyong Candles), Chris Holstein (Member for Gosford), Jillian Skinner (NSW Minister for Health), Darren Webber (Member for Wyong), Deb O'Neill (Federal Member for Robertson), Chris Spence (Member for The Entrance), Kathy Smith (Cancer Voices NSW), Chris Hartcher (Minister for Resources & Energy, Special Minister for State, & Minister for The Central Coast & Member for Terrigal) & Paul Tonkin

**Insert with this Newsletter :** contains details of the AGM, an invitation to the event at the CINSW, and a form to encourage recording your issues and ideas for 2012. The more we hear the voices of our constituents, the better we can progress them.

**Best Wishes and Thanks to All :** The 2011 CVN Executive Committee extends its very best wishes for the festive season to all our readers. Thank you for your ongoing support and interest, without which we would not be able to ensure the voice of people affected by cancer is really heard by decision-makers.

**Sally Crossing AM, Chair**

## **CVN NOTICEBOARD**

### **NOTICE OF ANNUAL GENERAL MEETING 2012**

**Cancer Voices NSW Inc invites you to attend its AGM on 8 February 2012 at 4.30 pm, at the Cancer Institute NSW, Level 9, 8 Central Ave, Eveleigh (short walk from Redfern Station, and ample refundable parking)**

Nominations for the Committee and for Office Bearers are also invited. Nominees should be supported by their voting member cancer support or advocacy group, on the form provided with this newsletter.

Please complete and mail to PO Box 5016, Greenwich NSW 2065 by 29 Jan, or bring on the day.

### **INVITATION TO ALL CANCER VOICES NSW MEMBERS!**

The brief formal AGM will be followed by an networking opportunity to meet and hear from senior Cancer Institute NSW staff, and CINSW CEO, Prof David Currow. And that may be followed by a glass of wine to welcome the New Year's activities and partnerships.

### **Learn About Advocacy and How to do It ! Consumer Advocacy Training (CAT) courses for 2012**

**16th and 17th March 2012 - Grafton**

**May 2012 – CAT for Aboriginal People – in conjunction with Cancer Council NSW and AMHRC**

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](mailto: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 this excellent introductory course

### **CVN Members across NSW - Join Grass Roots Advocacy in Action**

#### **Expressions of Interest to Participate in our “District Cancer Services Program 2012”**

We need enthusiastic “new blood” to energise our bi-monthly teleconferences which bring together CVN members from all over NSW. This gives them AND US the opportunity to hear about issues relevant to people affected by cancer, wherever they live.

If you have a toe in the water, or an ear to the ground in your Local Health District we would love to hear from you. The teleconferences are at no cost to you – kindly underwritten by the Cancer Council NSW.



## CVN COMMITTEE NEWS

**CVN Committee Business :** The CVN Executive Committee met on 28<sup>th</sup> September and 16<sup>th</sup> November. Having worked very closely with us to get the Palliative Care Campaign “over the line”, Yvonne McMaster stepped back from Committee membership to concentrate on palliative care issues as they arise. We thank her very much for her excellent work during this campaign, as the prime mover in gathering community and political support.

The last two meetings were addressed by invited speakers. On 28<sup>th</sup> September, James McGillicuddy of Affiliated Health Organisations spoke about the new health system arrangements and how they may impact cancer services. On 16<sup>th</sup> November, Jo Walton who manages the CanNET Program for CINSW, presented the excellent Canrefer Directory Website – and invited our feedback for fine-tuning.

**The AGM will be held on 8<sup>th</sup> February 2012 :** As Chair, Sally Crossing will provide the Annual Report 2011, which will be published in our March 2012 Newsletter. Nominations for the 2012 CVN Executive Committee are invited from all member groups. Please consider nominating if you would like to help us advocate for improvement in the journeys of people affected by cancer in NSW, and beyond. Use the nomination form enclosed, and ensure it reaches us prior to the AGM. If you would like to discuss any aspects of being an Executive Committee member, please call Sally Crossing on (02) 9436 1755 or Kathy Smith (02) 4344 5586. The Executive Committee meets centrally in the Sydney CBD bi-monthly.

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.

**Membership:** There are currently 86 group (voting) memberships and 396 individual members.

**Streamlining of CVN Databases :** Kathy Smith and Barb Galvin have reviewed our databases for Membership and Consumer Representatives, to make them work more effectively as a resource.

***CVN Consumer Reps – Please send your up-to-date email addresses for our records to - [info@cancervocies.org.au](mailto:info@cancervocies.org.au) ASAP, please!***

## CVN CONSUMER REPS IN ACTION

**“Nothing about us without us!”**

**Overall Consumer Representation :** We service 155 individual committees. 74 nominated individual consumers sit on these committees for 52 different organisations. (This does not include the reviewing activities for organisations such as Cancer Council NSW, NBOCC etc.)

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

## District Cancer Services (DCS) Report

The Area Cancer Service (ACS) Reps met by teleconference on 20<sup>th</sup> September, the last teleconference for 2011. We await confirmation of the new arrangements for Cancer Services Directors around the State in relation to Local Health Districts in which their cancer services now operate.

### Help us by Joining our “District Cancer Services Program 2012”

We seek expressions of interest to work on our “District Cancer Services Program 2012”. Let us know if you are interested in participating in a bi-monthly teleconference (at no cost), wherever you are in NSW, by emailing us at

**[info@cancervocies.org.au](mailto:info@cancervocies.org.au)**. This is a valuable forum for raising and discussing issues of concern and sharing information about the work of CVN. We learn so much through this process, which can direct and prioritise our advocacy: ed the “Palliative Care Campaign

## Consumer Advocacy Training

### Welcome CVN November 2011 Graduate Members!

We warmly welcome those “graduates” who have joined Cancer Voices as a result of the August training. This will be your first newsletter as members. Please let us know of issues you would like to raise with us, so we may include them for advocacy opportunities. 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.

### **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 be offering a CVN organisational view – only the Chair, or delegated Office bearers need to do that and

## **Consumer Involvement in Research (CIR) Program – News**

CVN's CIR Program has matured over the years since its development, initially in partnership with Cancer Council NSW. Its purpose, reach and processes are described in "A Decade of Success: Cancer Voices NSW 2000-2010", pp 22-23, in previous newsletters and our website. While we continue to nominate trained informed consumers to assist researchers by providing the consumer perspective, the following activities stand out this quarter.

- **COSA Enhancing Consumer Engagement in Research** On 29<sup>th</sup> September, Sally Crossing presented what has been achieved to date in this area, noting the long-term productive partnership between CVN and Cancer Council NSW. She also called for assistance to develop a national database for nomination of trained informed consumers to research projects. CVN has provided this service in NSW and beyond for some years, but we believe it would be better done nationally on a properly resourced basis, possibly using some of our robust processes, which CVN is happy to share. Sally has joined the Steering Committee.
- **Australian Cancer Trials Online (ACTO)** [www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au) "ACTO" provides consumer friendly access to information about available clinical trials, based on two major trials registries (ANZCTR and Clinicaltrials.gov). Cancer Australia, which maintains the website, called this meeting on 10<sup>th</sup> November to fine tune its content and functions. Sally Crossing was invited to speak

about the role of cancer consumers in the development of the website, and the search fields which they identified as being important. Elisabeth Kochman and Kathy Smith CVN also participated.

- **Personal Genomics in Cancer Care** : On 11<sup>th</sup> November, Sally Crossing presented "The Consumer Perspective" outlining our keen interest in, and support of, the progress of research into individualised cancer treatment, and our involvement to date in advocating for faster delivery. This meeting, hosted by Cancer Council NSW and the Garvan Institute, was attended by a good range of interested parties, and the outcome is to develop a national initiative to gain traction with national decision-makers and funders across Australia. Sally was invited to continue as the consumer representative in the next stages.
- **Policy for Consumer Engagement for Cancer Research Organisations** : Encouraged by Prof Rob Sutherland, Director of Cancer Research, Garvan Institute, CVN drafted a policy and recommendations for research groups seeking to establish a culture and process for meaningful consumer engagement. This may include a "Memorandum of Understanding" between the organisations. The concept has potential to be used with other cancer research institutes adjusted to their specific needs. CVN will so contribute these ideas to the COSA project (see above).

## **CVN ADVOCACY UPDATES**

### **Award for Outstanding Consumer Advocacy**

Cancer Voices NSW wishes to honour the memory, contribution and achievements of Sally Hodgkinson in a meaningful and enduring way. We have discussed options with her family, and colleagues have agreed to instigate an 'Award for Cancer Consumer Advocacy', to be named after her. This will be presented at our AGM on 8<sup>th</sup> February, with "Sally H" being it's first recipient, albeit posthumously.

During 2012 we will call for nominations for the most deserving recipient for the second Award.

### **Central Coast Cancer Centre Underway at Last**

5<sup>th</sup> October, 2011 saw the official start of construction of the new Cancer Centre at Gosford Hospital when Jillian Skinner, NSW Minister for Health, joined CVN's Kathy Smith to "turn the first sod".

There were actually 5 first sods turned on the day as Ms. Skinner and Kathy were joined by Deb O'Neill (Federal Member for Robertson), Paul Tonkin (Chair of the Central Coast Local Health District Board), and Lyn Smith (Wyong Candles). It could be said that a good time was had by all, but some of the ladies struggled to dig into the ground while balancing on their heels.

Also in attendance were the four State Government Members from the local area, local Councillors and many people who had worked with CVN on the campaign we ran for 4 years calling for public radiotherapy services to be located on the Central Coast.

Kathy is a member of the Project Control Group for the construction and commissioning of the Cancer Centre. Construction is due for completion in late 2012/early 2013 and there is no reason to think that this date will not be met.

**Out of Region Transport :** In the interim, CVN negotiated with the Local Health District in order to source transport for patients needing to travel to public radiotherapy treatment outside the Central Coast area. These negotiations resulted in two door to door services being operated to take patients for treatment at public facilities in Sydney and Newcastle. These services are being administered and operated by Coastwide Community Transport and Wyong Community Transport with buses and funding from Central Coast LHD.

**Public Radiotherapy at Macquarie University Hospital (MUH) :** The campaign for public radiotherapy services and the subsequent success of obtaining transport to public treatment led to an offer from Macquarie University Hospital Cancer Centre (MUH), a new state of the art private facility, to treat Central Coast radiotherapy patients at the Medicare rate. This arrangement between MUH and CVN Central Coast has been most welcome and will hopefully be renewed in the future to extend this offer until the Central Coast Cancer Centre is open for business.

MUH have on-site accommodation at very reasonable rates for cancer patients needing to travel to Sydney for radiotherapy treatment. The accommodation is set in the beautiful grounds of the university, and the cost includes 3 meals per day making it a very attractive rate.

**Central Coast Private Radiotherapy Petition :** A petition was organised by the newly styled private "Radiotherapy Institute" in Gosford for the NSW Government to pay their fees above the Medicare rate. CVN is aware that this is not possible

under Medicare arrangements. However, if exemptions were made it would have to be applied to all private RT facilities in NSW where public services do not exist. CVN does not believe this would be a proper use of the public health dollar.

Until the new Public Cancer Centre opens in late 2012/early 2013, Central Coast cancer patients requiring radiotherapy, who are either unable or do not opt to pay

the high cost of private RT services (offered by this partnership of private radiologists) have three options for accessing no-cost radiotherapy services (with free transport). These are : RNS Hospital, Macquarie University Hospital, and the Mater Hospital, Newcastle.

**Palliative Care Campaign 2011 :** This campaign has been our biggest in 2011, and what a successful one ! (See September Newsletter). However, follow-up and implementation of promises is imperative for success. We understand that funding which was removed from palliative care services in the Northern Sydney Local Health District is being restored.

CVN is now working with the NSW Ministry of Health to progress the broader commitments of the Hon Jillian Skinner MP, Minister for Health, made on 10<sup>th</sup> August. We want to see that funding of palliative care services throughout NSW actually meet the needs of communities, and that it is isolated for this purpose and not subsumed into general sub acute budgets of Local Health Districts. We are also keen to discuss workforce needs to ensure that the services can be delivered.

**Parliamentary Private Member's Statement praises Cancer Voices NSW :**  
*Editor's Note: Mr Kean is the MP for Hornsby, and his very kind words recorded in Hansard reflect his principle interest in the restoration of funding for Northern Sydney palliative care services.*

*Of course the next challenge for CVN is to see palliative care "fixed" state-wide.*

**CANCER VOICES NEW SOUTH WALES**  
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*Mr MATT KEAN (Hornsby) [6.54 p.m.]: I congratulate Cancer Voices New South Wales on the recent success of its palliative care campaign and for the incredible work that this organisation has been able to accomplish. Cancer Voices New South Wales, which recently*

marked its tenth anniversary, provides an independent voice for people affected by cancer. It serves as a valuable umbrella for support and advocacy groups and its ambition is to represent and support the needs of the 40,000 people who are diagnosed with cancer in this State each year. It does so through its three key programs: a consumer representatives program through which it regularly consults with experts in the field and involves them in the decision-making processes, a consumer involvement in research program that specialises in providing the thoughts of its members and consumers to researchers and their funders, and the area cancer services program, which sees regular engagement take place across New South Wales on local and regional issues that shape the direction of its future advocacy.

Some of the achievements of Cancer Voices New South Wales in its first 10 years include assistance in designing a number of the State's hospital cancer centres such as Royal North Shore, and the completion of the radiotherapy for public cancer patients on the Central Coast campaign, as well as successfully advocating to the Cancer Council New South Wales for financial assistance packages and pro bono and financial advice for cancer patients. But perhaps the biggest achievement of all was the success of the organisation's palliative care campaign, in which the cancer advocate worked with one of its members to restore more than \$1 million of funding that had been cut by the previous Labor Government. The inspirational Dr Yvonne McMaster spearheaded a campaign throughout northern Sydney, collecting more than 23,000 signatures for a petition that was tabled in Parliament in June by Premier Barry O'Farrell.

The campaign called for the immediate and direct provision of a level of funding to Hammond Care that would be sufficient to restore the delivery of palliative care in northern Sydney, and that funding of palliative care throughout the State reflected the true requirements of communities across New South Wales. I commend the Premier, Barry O'Farrell, and the Minister for Health, Jillian Skinner, for being as passionate on the issue of palliative care as I am. I congratulate the Government on restoring greatly needed funds so that such programs can continue in northern Sydney. These programs had been shamefully taken away by the previous Government, which was intent on penalising my community because of the way residents vote.

One case that illustrates why funds are needed for palliative care was broadcast last night on the ABC network's Australian Story program, in which I, along with a quarter of a million others across the State, learned the story of Gavin

Larkin, the founder of R U OK? Day. This courageous man, who has made a difference to the lives of so many, is currently receiving palliative care. Stories such as his highlight why funding for palliative care is incredibly important not only in northern Sydney but also across New South Wales. I send my best wishes to Gavin and his family—my thoughts are with you. I congratulate Cancer Voices New South Wales on its decade of success and I look forward to sharing its accomplishments over the next 10 years.

But any talk of the success of Cancer Voices New South Wales would not be complete without mentioning its outstanding chair and indefatigable campaigner Sally Crossing. Sally has used her own adversity to make a positive difference to the lives of people affected by cancer. After being diagnosed with breast cancer in

1995 Sally identified a lack of support for people who had been in her position. Sally had the vision, compassion and determination to address this situation and this is how the Breast Cancer Action Group was formed and how she became a leading light in Cancer Voices New South Wales. I commend Sally Crossing, Dr Yvonne McMaster and all those dedicated volunteers involved in the terrific work done by Cancer Voices New South Wales. As a community we owe them a tremendous debt of gratitude, and I am delighted to lend my support to this wonderful organisation now and in the future.

## **IPTAAS – Isolated Patients Travel & Accommodation Scheme :**

CVN has been invited to a briefing on 6<sup>th</sup> December on the promised improvements the O'Farrell Government made to the Scheme for travelling patients, and to provide feedback to the NSW Ministry of Health. This will give us an opportunity to put forward the remaining major aspects of IPTAAS improvement that our members have asked for. These are:

- Removal of the \$40 compulsory processing fee, introduced by the last Government, on top of travelling expenses.
- The complexity of the IPTAAS forms still needs to be addressed, and we have developed an outline of the basics as we see them, to assist in a review of the form.
- Removing the indefensible veto on IPTAAS assistance for people travelling to participate in clinical trials. As the NSW Minister for Health is also Minister for Medical Research, we hope she will be interested in reversing this impediment to research, and the very unusual view of the

IPTAAS administrators that clinical trials are “not treatment”.

- CVN seeks more flexibility regarding the distance travelled before IPTAAS can be claimed.

**New Position Statements :** CVN has developed two new Position Statements which now appear on the CVN website, and in this Newsletter. Comments and suggestions are always welcome.

**Access to PET Scans:** CVN has had an interest in this issue for many years’ and has advocated for better access and rebates than currently offered to people with cancer, especially those with advanced disease.

**Co-ordination of Care:** Another area of concern crystallised in our minds during Sally Hodgkinson’s last six months of life. The main challenge for Sally, her family, friends and CVN colleagues was the apparent lack of co-

ordination of her care. This, combined with constant uncertainties, was extremely distressing to her and those who wanted to help her. We would like to see “Guidelines” developed and implemented to greatly ease this part of the cancer journey.

#### **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](http://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.

### **Advocacy for Statistics?**

**Does cancer kill more Australians than any other disease?** YES. CVN has expressed concern to the Australian Bureau of Statistics (ABS) about their manner of presenting “Deaths from Cancer”. Currently these are not aggregated – ie they are separated into specific cancers like lung, breast, bowel, prostate, etc. When journalists use statistics presented in this way, they are not aware

that when aggregated generically as cancer (as occurs for other diseases), cancer is the biggest killer of Australians.

We think this is very important information for understanding the impact of cancer on Australians’ lives, for planning of cancer services and allocating research funding. The ABS responded very positively and is looking to see how this confusion may be addressed, while maintaining parity with international reporting requirements.

### **Private Health Insurance (PHI) for Cancer Treatment :**

CVN is aware of increasing reports of excessive gap payments for cancer treatment, particularly radiotherapy, and to a lesser extent chemotherapy and day surgery. We are researching the policies of the five major private health insurers to ascertain whether any policies can cover this kind of out-patient hospital cancer treatment. While we understand that out-patient (ie not overnighting in a hospital, just visiting it by day) treatment is usually not covered, CVN is

exploring what could be done to change this. It may be good to be able to choose your doctor, but if his/her treatment within the hospital's walls is solely at your expense, this may come as a nasty and burdensome surprise.

We hear that many cancer patients are not aware that the doctor they have been referred to for radiotherapy is a private practitioner - Medicare rebates only apply to a portion of his/her professional fee, not the actual treatment. Should all privately insured patients insist on radiotherapy at public hospitals as public patients, as is their right as taxpayers? This would put a lot of pressure on the public purse, and strain physical resources as well.

CVN is consulting our PHI industry adviser and Cancer Council NSW with a view to making a case for discussion with the PHI industry.

**Your views and experiences would help our potential advocacy on this**

**PBS Deferrals Restored :** Consumers Health Forum of Australia (CHF), the national health consumer organisation to which we belong, has thanked CVN for support of CHF’s successful PBS Deferrals Decision Campaign. On 30<sup>th</sup> September, the Prime Minister and Minister for Health, the Hon Nicola Roxon MP, announced that all the medicines deferred by Cabinet in February would be listed on

the Pharmaceutical Benefits Scheme – an excellent outcome. Some of the drugs affected are used in the treatment of cancer or for treatment of side effects.

## **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:**

- Tripartite National Strategic Plan for Radiation Oncology, Faculty of Radiation Oncology, RANZCR
- Garvan: Consumer Engagement Policy & Recommendations
- NHMRC: Ethical Framework for Palliative Care
- NSW: Framework for Advance Planning for End of Life
- NSW: Outstanding IPTAAS Issues for Cancer Patients

### **Speaking:**

- CAT Course, 24 & 25 Nov
- CA: Aust. Cancer Trials Expert User Group, 19 Nov
- COSA Consumer Engagement, 29 Sep & 9 Dec
- USyd Second Yr Medicine Course, Consumer Advocacy Lecture, 24 Oct
- USyd Post Grad Public Health Students: Internet Mentoring PUBH5019 Cancer Prevention & Control, 11 Oct
- USyd Doing Drugs: The Ethics, Economics & Politics of National & International Medicines Policy, 29 Nov

### **Major Meetings:**

- CINSW Canrefer Expert Reference Group, 7 Sep
- CINSW CEO, D Currow, 8 Sep
- CINSW CanNET NSW Committee, 12 Oct
- NSW Health D D-G, Dr N Lyons re Pall Care, 13 Sep
- Macquarie Univ.Hospital: CEO Carol Bryant, 26 Oct
- CCNSW Consumer Engagement Project Proposal, 22 Nov
- CCNSW Financial Assistance Roundtable, 14 Oct
- Cancer Australia ACTO Expert User Group, 10 Nov
- CCNSW CVN Joint Execs Meeting, 7 Dec

- NSW Ministry of Health Palliative Care Expert Advisory Group, 7 Dec
- NSWMMH, IPTAAS Briefing & Feedback, 6 Dec

### **Events:**

- Gosford Cancer Centre, Turning the Sod, 5 Oct
- Consumers Health Forum Leaders' Training 14/15 Sep
- Kolling Institute RNSH Research Overview 11 Oct
- Garvan CEO of UICC, 10 Oct
- Aust Fin Review National Health Conference, 17 Oct
- International Assoc for Public Participation Workshop: 19 Oct
- PainAustralia AGM & Update, 20 Oct
- Dying with Dignity Public Forum NSW Parliament 15 Nov
- Palliative Care NSW Policy Launch, 22 Nov
- Chronic Disease Conference, 24 Nov

### **Publications / Media:**

- CVN Media Release re Central Coast Private RT petition
- Jane Elix Blog: Women's Leadership Profile of Sally Crossing
- Letter to SMH re Blackmores' agreement with Pharmacy Guild
- Letter to SMH re Value of Consumer Involvement in Research

### **CVN Member Named "Volunteer of the Year"**

**Year"** : CVN member Barb Galvin was awarded "Central Coast Volunteer 2011" for fund-raising activities for "The Shirley Shuttle Cancer Patient Service" (within the Cancer Transport Action Group, a community organisation which raises funds for patient transport). Barb donated the original vehicle in memory of her late Mother 'Shirley' who died from colon cancer in 2006. Barb continues to raise funds to maintain and extend the service within the Central Coast to take cancer patients to and from medical appointments. Well done !!



## WHAT'S HAPPENING AT STATE LEVEL?

### Cancer Council NSW

The Cancer Directory is now LIVE  
[www.cancerdirectory.com.au](http://www.cancerdirectory.com.au)

Launched at the **Clinical Oncological Society of Australia (COSA)** Conference in Perth from 15<sup>th</sup> to 17<sup>th</sup> November 2011, the website will be promoted initially to health professionals to use as a resource when working with people with cancer, family, friends and partners of people with cancer, and the general public.

Those accessing the website will be able to:

- Search for a resource to prevent, screen for, diagnose or treat any cancer,
- Submit a resource they publish, after registering with CVN,
- Suggest a useful resource from another organisation, and
- Register for an e-newsletter.

Over the next few months the website will be expanded to include other resources, as there are a number of resource gaps for some cancer types that are less common or for specific population groups. Currently there are over 1500 printed, AV and electronic resources collected from over 80 governments, Cancer Councils, large health services and major not-for-profit organisations.

Cancer Directory is a n  
managed and maintain  
(CCNSW)

(Editor's Note: CVN will be submitting *A Decade of Success: Cancer Voices NSW 2000-2010*, for inclusion)

## Cancer Institute NSW (CINSW) CANREFER – A real Referral Directory has arrived! - [canrefer.org.au](http://canrefer.org.au)

*(Editor: Cancer Voices warmly welcomes the arrival of Canrefer. Having access to information about cancer specialists across NSW, especially those working in multidisciplinary teams, was a major piece of successful advocacy for CVN over the last five years. Originally there were concerns about our identified consumer need for*

*names and contact details of individual cancer specialists, but we are delighted that this vital information is now accessible for cancer patients and their referring doctors.*

*Thank you CINSW for listening and making it happen. CVN has been involved throughout the website's development. CVN members are welcome to provide feedback directly to CINSW, or through us at [info@cancevoices.org.au](mailto:info@cancevoices.org.au)*

Canrefer is a directory set up by the CINSW to help general practitioners, other health professionals, patients and family members, find cancer services by cancer type and location in NSW.

The information in Canrefer will help general practitioners in referring newly diagnosed cancer patients to specialists attached to [multidisciplinary teams](#) and support timely referrals as early on in the cancer Journey as possible.

The development of online cancer services directories for all Australian States and Territories began as part of Cancer Australia's [CanNET program](#). The CINSW developed Canrefer, the NSW directory, with the assistance of cancer services personnel and support from NSW Health through the [Health Establishment Registration Online \(HERO\)](#) project.



- Use the simple keyword search located at the top of every screen,
- Use the *quick search* to enter basic location, cancer type and/or service type criteria, and
- Use the *advanced search* to search by location, keyword and/or multiple service and cancer types.

Find out more information about the services that can be found within Canrefer re : specialists and multi-disciplinary teams, breast cancer units, cancer genetic services, chemotherapy units, radiation oncology units, and palliative care services.

### Primary brain tumour nursing module :

Nurses and health professionals will now have access to a brain tumour nursing module to support the care of primary brain tumour patients through all stages of their cancer journey. Developed by the NSWOG Neuro-Oncology, the online module features video case-studies following the story of

Martin, a 49-year-old man diagnosed with a primary brain tumour. It begins with his presentation to an emergency department after experiencing a seizure, with the last clip canvassing Martin's deterioration and behavioural changes as seen by his family.

View the resource online at

[brainmodule.cancerinstitute.org.au](http://brainmodule.cancerinstitute.org.au)

### **Evidence based guidelines for nutritional management of patients with head and neck cancer**

**neck cancer** : Australia's first evidence-based guidelines for the nutritional management of people with head and neck cancer have been launched. The guidelines were the idea of NSWOG Head and Neck member, and senior oncology dietician, Merran Findlay – and were supported by the Cancer Institute NSW under the auspice of COSA. They have been internationally endorsed and will influence clinical practice to ultimately prevent malnutrition in this patient group.

**Australian Mesothelioma Registry** : The Australian Mesothelioma Registry (AMR) has begun collecting important data about all Australians diagnosed with mesothelioma from 1 July 2010 to inform the development of policies to best deal with the asbestos still present in Australia's buildings and environment. The collection includes a patient survey to capture important information about occupational and environmental asbestos exposure. For more information, visit

[www.mesothelioma-australia.com](http://www.mesothelioma-australia.com)

## **WHAT'S HAPPENING NATIONALLY?**

### **Cancer Australia (CA)**

CA's National **Framework for Consumer Engagement** was published in October, and is available at [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au) or by contacting CA for a hard copy. CVN reps were closely involved in the development of the publication, and are very pleased with the final outcome. The challenge now is for CA and other cancer world decision-makers to implement the principles of the "Framework", in consultation with recognised cancer consumer organisations.

### **Consumer Engagement in Cancer**

**Research:** Cancer Australia has provided a grant to the Clinical Oncology Society of Australia (COSA) to develop a Consumer Engagement policy for its COSA's Clinical Oncology Groups, which include consumers, some of whom are CVN members. We are participating in the development of this policy,

and are hopeful that it may become more broadly applicable.

### **National Training for Cancer Consumers:**

We understand that Cancer Australia is looking for proposals to develop a training framework to implement some of the principles of the Consumer Engagement Framework. CVN has expressed interest in assisting in the development of this, along with experienced partners. We will suggest that focus should be applied on how to encourage stakeholders to understand meaningful consumer engagement and how to go about it, building on tried and proven processes such as those developed by CVN over the last eleven years.

**Cancer Voices Australia** : CVA's AGM was held in Perth on 14<sup>th</sup> November, but was not attended by CVN, or Cancer Voices SA as governance status was unclear.

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## **CVN POSITION STATEMENTS For Info & Comment**

### **1. ACCESS TO POSITRON EMISSION TOMOGRAPHY (PET) SCANS FOR CANCER PATIENTS**

**ISSUE** : Access to Positron Emission Tomography (PET) is denied to many cancer patients due to cost, when not Medicare rebated, and to distance. Many more would benefit if access was improved.

**BACKGROUND** : PET is an exceptional functional imaging procedure that provides a more accurate picture of the extent of cancer and response to therapy, compared to more routine tests that are commonly relied upon to guide clinical treatment decisions. PET is useful for detecting metastases which do not show up on CT or similar scans, assisting decisions about type of treatment to follow.

PET not only supports better patient outcomes by allowing more personalised delivery of cancer care, it helps save scarce healthcare dollars. For example, in 2007 the Medicare Service Advisory Committee (MSAC) review found adding PET to treatment planning in one cancer alone (recurrent colorectal cancer) could decrease costs Australia wide by between \$6,113,000 and \$10,187,000. At the same time 20 to 35% of patients could avoid surgery.

**CURRENT SITUATION** : MSAC has reported that PET is likely to be cost saving in staging lung cancer and oesophageal cancer as well as in the evaluation of recurrent ovarian cancer and potentially melanoma, but has rejected evidence for

a number of other common cancers, including breast and prostate. Several of these decisions are being questioned by experts and consumers.

The MSAC process of data collection, from only 7 designated sites in Australia, to measure the usefulness, effectiveness and cost efficiencies of PET in other cancers, has been reported to be unsatisfactory.

There are unacceptable time frames for the implementation of a MSAC recommendation for a cancer indication. In many cases this can be up to 40 weeks. MSAC consideration itself also takes too long – up to four years. While this situation is apparently being addressed following the Health Technology Assessment (HTA) Review 2009, to which Cancer Voices NSW made a submission, results for people with cancer are yet to be seen. Rural and remote cancer patients suffer a greater disadvantage both in access and investigation and treatment options. It is plausible that cancer outcomes would improve considerably for rural and remote patients if they had better access to PET/CT and the treatment benefits that follow from more precise characterisation of each person's cancer, therapeutic needs and response.

#### **RECOMMENDATIONS :**

- The current Terms of Reference and data collection processes for the MSAC of PET/CT need to be reconsidered in the light of national and international literature that proves that this technology has the potential to positively influence the management of many of the major cancers, and deliver better patient outcomes now and in the future.
- The Federal Government must be urged to grant affordable access to PET/CT for all cancer types where effectiveness is apparent, with particular emphasis on access for rural and remote patients.

## **2. CARE COORDINATION TOWARDS END OF LIFE**

**ISSUE :** Coordination of care for people with advanced, quality of life-limiting cancer is hard to get.

This gap is distressing and destabilising for the patient, their family, carers and friends.

**BACKGROUND :** CVN has heard from several members who are very concerned about the lack of coordinated treatment and care when they become seriously ill or immobilised as a result of their cancer. The cancer care centre and its specialists are no longer the “managing

agent” and an unexpected and confusing journey between hospital, rehab facility, home, palliative

care, ICU and back again may begin. A characteristic of the problem is poor communications between facilities, specialists and the person's GP and family/ carers.

**PRESENT POSITION :** Medicare provides rebatable items (GP Management Plans and Team Care Arrangements) which can be used for coordination planning. NSW Health is introducing the NSW Connecting Care Program, whose aim is to improve coordination and self management in chronic disease, including cancer. NSW Health has recently published an excellent draft Framework “*Advance Planning for Quality Care at End of Life*” (Sep 2011), which summarises the issues and recommends key priorities for implementation. CVN has made a submission as invited.

GPs are expected to play a coordinating role, but once the condition requires hospitalisation, rehabilitation, palliative care etc, the GP has trouble keeping up with events. It becomes difficult for consumers to access the required services without a coordinator who is aware of the condition, prognosis, requirements and service/ care options.

#### **RECOMMENDATIONS:**

- Best practice guidelines be finalised and promoted to GPs, cancer care centres, rehab centres, palliative care services and consumers
- Case conferencing be organised as soon as need for coordination can be identified
- Triggers or “flags” should be identified and circulated to care providers as functional status begins to decline
- Oncology nurses, where they exist, to be considered as ideal coordinators
- GPs to be alerted by cancer specialists that an advance care plan should be developed, nominating who has responsibility to ensure coordination planning
- NSW Health to review “end of life” related services to assess gaps, with a view to ensuring resourcing (financial and workforce) for these services is adequate.

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### **THANKS**

**Cancer Voices NSW greatly appreciates the assistance given by the Cancer Council NSW in the printing and posting of the Cancer Voices Newsletter.**

**Contact CVN: PO Box 5016 Greenwich  
2065**

**[info@cancervoices.org.au](mailto:info@cancervoices.org.au)**

# VALE Sally Hodgkinson



We were very saddened to hear of the death of Sally Hodgkinson, "Sally H", on 28<sup>th</sup> September, as a result of breast cancer. "Sally C", presented a eulogy at the funeral on 6<sup>th</sup> October, printed below. Several CVN members and stakeholder colleagues from organisations Sally had worked with such as CCNSW, NBCF, CINSW and TROG farewelled her too. Sally's family, with whom we had become close over her last months, invited people to send a donation to CVN in lieu of flowers, which many did. Thanks !

## **Dear Sally H - here are some memories**

**from Sally C.** Having two long tall Sallys driving the operations of CVN meant we needed those add-on initials badly. I am now always Sally C, even though Sally H has left us. By dying she has physically left us, but Sally was such a pillar of willingness, intelligence, determination and straight talking, that she is firmly planted in the organisation's fabric and will remain there.

She is immortalised in our recent publication *A Decade of Success: Cancer Voices NSW 2000-2010*. A small record of someone who did a great deal for a large number of people.

I would like to share a few quotes from the many email messages that flooded my email box since Sally's death :

- *Sally's efforts were greatly valued and appreciated by us, not least for her indomitable spirit, intelligence and insight, calm sensible wisdom, unflappable cheerfulness, persistence and willingness to help out wherever she could. Sally will be greatly missed..*
- *Her death is a great loss to the cancer community and I know it will be keenly felt by all at Cancer Voices. I knew Sally H for a relatively short time, but she left a very strong impression on me. Her decency, her hard work, her intellect and her community spirit were truly inspiring.*

- *Can't imagine what a huge gap her passing will leave in the mountain of advocacy and administration which unremittingly goes on behind the scenes to ease the path of those 'in the cancer scene'.*
- *She was always such a stalwart, and a loyal and trusted friend to you and the Cancer Voices cause. You will miss her very much. My thoughts are with you and the team.*
- *Sally has contributed a huge amount of valuable advice and support to TROG (Trans Tasman Oncology Group) over many years in her role as our consumer adviser and also as a Company Director. .... I will personally miss her very much as I valued her friendship and support.*

Sally was first diagnosed with breast cancer in 2001. We met initially through the Breast Cancer Action Group NSW, the training ground for a number of us now working with Cancer Voices NSW.

Here are her own words about why she became interested: "I thought I could use skills developed as a senior public servant for the betterment of other people affected by cancer of all the different types, not just breast cancer". Another reason was "to keep my brain going" which she said her involvement in BCAG and Cancer Voices did in spades!

Apart from being the same height and having the same cancers, we Sallies both had careers in the NSW public service – during which we learned the subtle and not so subtle arts of government and politics – handy attributes for an advocacy group. Because of this, and her keenness to help us operate well, a major bond formed between us. We soon learned each other's strengths and weaknesses, and played to the strengths.

Sally H did so many things for Cancer Voices – Hon Secretary, Membership Database Manager, Consumer Reps Program Manager, formatter of the newsletters, author of a number of Position Statements with a special interest in radiotherapy, imaging, cancer research and rural and regional issues. Sally also became a senior voice for people affected by cancer on a number of major committees, working parties, Boards and research projects. Quite a few of those who worked with her on these are here today. This was Sally's "cancer world", one of several she maintained with equal ability.

We all benefited from the friendships that grew as we worked together for a common good cause, about which we knew a lot - personally and more broadly. People with cancer have an immediate

bond with each other and that gives us the basis for building much more.

So Sally H, thank you for sharing a major part of your recent life with Cancer Voices NSW. We honour you and thank you. Your huge contribution and good friendship will not be forgotten by us or by the “cancer world” stakeholders you tirelessly work with to make a real difference to people affected by cancer.

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need for a dedicated committee to “oversee the compilation and review of the evidence around [prostate cancer] screening to develop a program that maximises the benefits and minimises the harms”.

## **BITS & PIECES :**

### **Consumer Movement Leaders – Jane Elix’s**

**Blog :** After experiencing breast cancer in 1995, Sally Crossing became a tireless advocate for improving cancer treatment and care. She gave up her career to establish the Breast Cancer Action Group NSW, which became a powerful and effective consumer organisation. She now chairs Cancer Voices NSW and the newly established Health Consumers NSW. She stresses the value of a collaborative style of leadership and the rewards that come from working with others. Read Kate Moore's profile of Sally at

<http://janeelix.wordpress.com/2011/10/24/sally-crossing/>

### **Public Health - Gene Rights Ban Rejected (SMH, 22<sup>nd</sup> Sept, 2011, p.5)**

A proposed ban on the controversial patenting of human genetic material has lost the support of a Senate committee which threatens to renew the intense debate that has pitched patients and doctors against researchers and biotech companies. A narrow majority of the Senate Legal and Constitutional Committee in a report tabled last night, recommended against a private member’ bill which would have outlawed the patenting of human genetic material. The issue of patent rights for naturally occurring human genetic material isolated by biotech companies has fuelled outcry from patients and doctors alarmed at the prospect of patents on human tissue and the resulting high priced tests for cancer and other diseases. (*Ed: The battle is definitely not lost!*)

### **Prostate Cancer Foundation of Australia Supports Calls for National Protocols on Prostate Cancer Testing (Sydney, 28th Sept, 2011)**

Prostate Cancer Foundation of Australia (PCFA) has commended Professor Bruce Armstrong on his recommendations for establishing national protocols for prostate cancer testing to help regulate the guidance given to men about the prostate cancer testing and treatment. Professor Armstrong, a respected epidemiologist from the School of Public Health at the University of Sydney, expressed the