IN THIS ISSUE:  
- CV on line  
- Donation time  
- NSW Cancer Survival Study  

Editorial

Cancer Voices on line

www.cancervoices.org.au

WE are proud to advise our members that Cancer Voices NSW now have a very beautiful green web site at www.cancervoices.org.au. This has truly been a team effort, resulting in good text and excellent design. Particular thanks to Nola Norris for contributing her skill - and great photos by Norman Thompson. Many thanks to all involved!

Now whenever you want to explain what we do and how to join us, just pass the magic web address around. We have also updated and reprinted the leaflet with most recent issues, contact points etc; a copy will come with this Newsletter, but do ask for more if you can use them.

Also:
New email address:  
info@cancervoices.org.au
New postal address: PO Box 138, Gladesville NSW 2111

Money Matters

WE are also asking for 2002 donations with this issue and include a form to return with your donation. Please use the blank side to advise us of any issues you would like us to look into. As we are an entirely voluntary group, we do seek donations once a year to cover our core costs.

On the subject of money, we are delighted to announce that Sandra Jew has joined us as Treasurer. We feel very confident that we are now in the best of hands in this area. Having just paid $550 for compulsory public liability as an incorporated association - our biggest expense to date - we have heard that the NSW Dept of Fair Trading has now removed this requirement. Cancer Voices had made a representation to the NSW Minister, and bingo! (It was probably one of hundreds of similar protests.)

Meetings

SINCE the March Newsletter, your Steering Committee has met on 27 March, 8 May and 19 June. Keen participation continues and we have invited “stakeholders” to address us briefly each time. The NSW’s Cancer Council CEO Dr Andrew Penman attended in April to discuss our mutual interests, and Ms Val Noble from the Quality Program in Western Sydney and Wentworth AHS, a project funded by TCCNSW for $1.5m. This proves to be a good way to meet decision-makers in the cancer world and for them to understand us.

Our first AGM will be held on 19 February 2003. At this meeting we will elect office bearers and the committee for the year. The December Newsletter will carry information about nominations and voting by member groups.

Consumer Representation

WE have finally convinced The Cancer Council Australia that they should invite a consumer representative to join their board. It took 2 months of advocating, despite the fact that CVN reps have the only consumer spots on TCCA committees. We imagine that a rep from the Cancer Advocacy Network (launching in November) will be nominated for this. Some organizations take longer than others to understand how much we are needed!

Carole Sherringham and John Tong now look after our consumer advocates’ register and Carole coordinates the requests for reps, providing a report on this each CVN committee meeting. Thanks to those of you who are out there working on our behalf already. - 20 of you to date.

Sally Crossing
Recent Reports of Interest

Living with Cancer Conference : Report of Proceedings, TCCA

CVN was asked by representatives on the TCCA Patient Support Committee (whose brainchild was the February conference) to attend. Over 15% of consumer attendees were from Cancer Voices NSW (9 of the 58). Despite this, and our participation in the lead-up TCCNSW Consumer Forums, we were not offered a formal role in the proceedings (dinosaur country?). But our presence was memorable and our special edition conference Newsletter was well received. Grumbles aside, the report contains a lot of useful stuff for consumer groups and for the national, state and territory cancer organizations to use in their advocacy activities on behalf of people affected by cancer. If they need a little reminding, we are there to help. Copies can be obtained from TCCA (02) 9380 9022.

Optimising Cancer Care in Australia

The May Draft "not for citation" version of this excellent summary of what ails cancer care in Australia and recommendations to address the identified problems, is out for wide stakeholder comment. CVN has expressed its strong support. The Cancer Council Australia and the Clinical Oncology Society of Australia identified the need for this report at the instigation of their Medical and Scientific Committee. This is something for which your representative Sally Crossing had been lobbying for some time. With Sally as part of the Steering group that oversaw its development, CVN has had good input. Other CVN member groups have also strongly supported it. This is the first attempt to consider a big picture national approach, which we feel, could improve equity of access to best practice cancer care for all Australians. National benchmarking would help guide state health services. We hope that the new Federal Health Minister will favourably consider its recommendations for such a big constituency (about 90,000 Australians are diagnosed with cancer each year) and many more of us that live with our disease.

Presentation to CERP Conference

We think this may be a first for a voluntary cancer advocacy group. A founding member group of CVN, the Breast Cancer Action Group NSW, was invited to present their consumer initiated survey of their members’ views of cancer experiences to the Behavioural Research in Cancer Control Conference (organised by the CERP and held in Newcastle 17-19 April). The presentation was very well received and the authors invited to present to other conferences later in the year.

Quality Management Workshop

This workshop was conducted by the Cancer Council of NSW on 11 June 2002 and moderated by Dr. Norman Swan. Four representatives from CVN attended. Topics discussed included: An overview of Quality Management (NSW Health Department), Matching Quality with Care (CVN), Errors in Cancer Care and using the information to move forward. All sessions were informative and thought provoking with Dr. Swan obtaining a guarantee from all in attendance that the outcomes of the conference would be monitored and acted upon.

Call for interest in new Cancer Groups

One of CVN’s objectives is to encourage the development of cancer consumer groups for particular cancers that do not yet have any representation, networks or support groups. We invite you to let us know if you would be interested in starting up an informal group of people who have experienced your cancer, if no linkage yet exists. We may then be able to connect you to some of our individual members, if they agree, and gather together a small critical mass, which might then be able to join forces or Voices. For example, the national, but Perth based Gynecological Awareness Information Network (GAIN) is keen to gauge interest in a NSW group. This could link with both CVN and GAIN.

Consumer Advocacy Training

The fourth and final day of this course - begun last year - was held on 18 May. Another excellent day much appreciated by the graduates. Thanks to the Cancer Council NSW, and particularly to Margaret Duckett, the convenor. Of great interest were the presentations by the members of the Department of Health and the NSW Health Care Complaints’ Commission who told us how it really is, and how to navigate bureaucracy. We also updated and grouped our current issues for attention and pursuit. We are looking forward to announcing another CAT in F/Y 2002-03.
NSW Radiotherapy Services

CVN has been advocating busily on this front. An April letter to the NSW Minister for Health (unanswered to date) seeking to ascertain the fate of the 2001-06 NSW Radiotherapy Plan was followed by a $30 Freedom of Information request to the Department of Health to release the waiting times experienced by cancer patients around the state. From the latter we have been advised that the NSW Health Department does not collect or analyse waiting times for radiotherapy in NSW. The Dept. does not prepare weekly or annual reports on radiotherapy waiting times. So clearly there is no measurement of this issue by those who are supposed to be managing it. We are also endeavouring to find out whether any of the Federal Budget’s $72m for radiotherapy is destined for NSW. We will advise any results when to hand.

Pharmaceutical Benefits Schedule

As high cost, targeted drugs are set to become the new most effective cancer drugs in the not very distant future, and as we can’t expect the off-PBS Herceptin solution again, the way the PBAC makes these decisions is of great interest to us. We are also endeavouring to find out whether any of the Federal Budget’s $72m for radiotherapy is destined for NSW. We will advise any results when to hand.

Cancer Priorities 2001-03

Max Gardner attended this two-day conference in Canberra designed to discuss the recommendations of the Cancer Strategy Group. This is a process that CVN has not been altogether happy about, due to its limited terms of reference and distance from political will.

NSW Health Budget

Nothing specifically in this for improving cancer services which is a disappointment. Sally Crossing attended a briefing for health consumers in the Health Minister’s Office on 4 June, and during Q & A asked whether the Budget contained more funding for the very under-funded IPTAAS (travel and accommodation) program. This is of importance to many rural and remote cancer patients. The answer was “No”. CVN will continue to call for a review of IPTAAS to make the criteria more practical and increase funding.

Consumer Representation Policy

It is CVN policy to seek consumer representative places at all relevant seminars, workshops and conferences. We expect that the organising body will absorb any registration fee, to ensure that volunteer consumer representatives of CVN can attend without that often-considerable personal expense. We welcome offers to cover travel costs. We believe such assistance, which ensures our participation and input, is in the interests of both CVN, its members, and those stakeholders who arrange such events.

Insurance Difficulties for People who have experienced Cancer.

A number of health consumer groups, organised by the Chronic Illness Alliance, are meeting on 19 July. We will share and identify the major problems our members’ face with private health insurance, due to their condition or past history. We have been invited to raise these with the industry association, following Sally Crossing’s address to them about insurance issues for cancer consumers earlier in the year.

You can help us make progress on 19 July by sending us (by 10 July) any personal stories of problems you have had to overcome (or not been able to) with your private health insurer. If you prefer your name to be withheld, we will guarantee to do so. Real stories will make our submission more compelling and evidence based - even if anecdotal at this stage. Thank you in advance. Please send or email any details to CVN.
The NSW Cancer Council’s behavioural research unit, the Cancer Education Research Program (CERP), is undertaking research about cancer survivorship. The NSW Cancer Survival Study aims to learn more about the physical, emotional and social effect that cancer has on survivors, the issues they face and the type of help they need. This research will help the Cancer Council NSW to develop new programs and policies to better assist cancer survivors. CERP recognises that the views and experiences of consumers are important in informing aspects of its work and ensuring that the research it undertakes is relevant.

In December 2001, CERP approached Cancer Voices NSW for assistance to test the acceptability of the NSW Cancer Survival Survey in terms of its format, length, clarity and relevance to cancer survivors before being administered to 1,000 survivors in the main study. The NSW Cancer Survival Survey is a 142 item self-report survey assessing cancer survivors’ perceived needs, overall health, emotional well being, access to social support, coping style and general background.

50 members of Cancer Voices NSW completed the NSW Cancer Survival Survey and a survey evaluation form. Overall, 18 people thought there were not enough response options and 12 people thought the survey was too long. Only 4 people needed any help to fill the survey in and only 2 felt worried after filling it in. Almost everyone reported that the questions were easy to understand, although several respondents contacted us to clarify the context or timeframe of the questions. Many respondents welcomed the opportunity to report their cancer experiences.

As a result of the information collected and the feedback provided, substantial changes were made to the survey including:
- Revising response options and providing examples for some response categories
- Reformatting the survey to reduce its length
- Adding statements to clarify that the questions are in relation to cancer and emphasise that the research is focused on the issues faced by long-term survivors now
- Adding statements advising participants that they don’t have to complete the whole survey in one sitting but can fill it in over a number of days
- Adding a statement to the introduction of the demographics section to inform participants that clinical details about their cancer such as cancer type and date of diagnosis will be obtained from the NSW Central Cancer Registry.

The researchers believe the survey is now a more user-friendly instrument for collecting high quality and relevant information on the experiences of cancer survivors. The main study has now commenced and to date, the survey has been sent to 60 of the targeted 1,000 long-term cancer survivors. The Project Team at CERP would like to extend their thanks to the members of Cancer Voices NSW who participated in the pilot testing. Further information about the NSW Cancer Survival Study is available from Allison Boyes (Project Manager) or Alison Zucca (Project Officer) on Freecall 1800 246 337. A copy of the pilot study report and the revised NSW Cancer Survival Survey are available from Cancer Voices NSW. (Allison Boyes, Afaf Girgis, Alison Zucca)

---

**Membership**

Our membership sits at over 70 cancer consumer and support groups, and well over 100 individuals and health professionals (associate members). Welcome to all our new members who are receiving this newsletter for the first time.

Remember that new members are most welcome and membership application forms are available either online in our new website or from the contact addresses listed earlier in this newsletter. Would all members please advise us when their details change as much time is spent trying to trace members when emails or normal mailings are returned.