

 **Message to members**



Returning to the Chair of Cancer Voices NSW after a two year break, it's a good moment to reintroduce myself and offer a few reflections and ideas for 2014.

I've been closely involved in cancer consumer advocacy since 1997 when I began the Breast Cancer Action Group NSW, followed by Cancer Voices in 2000. Later came the establishment of Health Consumers NSW, and last year I spent, with others, time restoring Cancer Voices Australia as the national voice of people affected by cancer.

It seems I can't get it out of my blood. Luckily I have had many years of survival of our mutual disease, cancer: a diagnosis of early breast cancer in 1995, metastatic in 2004 and most recently, an unwelcome progression. Being awarded an AM – Member of the Order of Australia in 2005 was hugely encouraging – that this kind of giving back was formally appreciated by my country.

Every now and then we need to ask ourselves why we become active in cancer consumer advocacy. I think the answer is that this kind of advocacy really works. It's not rocket science, or even cancer research (though we are keen about that too). It's that with persistence and patience, alerting and steering decision-makers towards what people affected by cancer need, want and hope for, is a win-win thing to do. One of its beauties, apart from satisfaction when we do have success, is that it does not require expensive resources – just passion, commitment and awareness of real needs and how the system works. Sign up for a Consumer Advocacy

Training course (see Noticeboard on page 2) for some guidance about advocacy and the systems in which we need to operate.

Of course, some of our requests to government are expensive, and we need to be aware that they must be a good investment for our society as well as people affected by cancer – remembering that cancer is now the biggest cause of death for Australians. Examples of this include achieving the long overdue Comprehensive Cancer Centre on the Central Coast – actualised as a result of Cancer Voices efforts led ably by Kathy Smith. Governments, both national and state, eventually accepted that this investment was not only necessary, but would pay dividends on a number of levels.

You will read in this issue that we have become interested in the debates around best practice consumer engagement in research, and a more immediate issue - for many of us – access to high cost cancer drugs.

So, I am delighted to have been called back to lead Cancer Voices. Our Executive Committee made confident and meaningful strides under Kathy's leadership, and I am relieved that she is continuing on the operational team to give us sound advice on all aspects of our efforts.

Remember, we are here to serve your interests, and those of the many others like you – currently over 40,000 diagnosed each year in NSW and rising. There are a lot of us and our voices need to be heard. With your help and support, they will be!

I end this message with a comment which has real significance for an organisation like Cancer Voices – not to mention the many other consumer groups: *“there is a moral duty to make processes as inclusive and accountable as possible, but also because doing so makes processes more useable, efficient, transferable to other jurisdictions, and acceptable to stakeholders”*. It sounds a bit turgid, but it does hit the spot about why we believe our advocacy is worth pursuing.

Very best wishes
Sally Crossing AM

Chair



Advocacy Training 2014

Next Workshop: 2 & 3 May, Griffith

The next Advocacy Training Workshop for Sydney will be held in August – details will be on our website as soon as we have them

To help you speak up about issues affecting people with cancer and to learn about how to be a consumer representative.

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

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

- *Become active and effective advocates for better cancer policies and services*
- *Approach consumer representative work with more confidence*
- *Understand how “the system” works, and how you can influence decision-makers*

Apply online: <http://canact.com.au/advocacy-training/>

For further information: Policy & Advocacy Unit, Cancer Council NSW

Phone Carolyn: (02) 9334 1855 or Marion (02) 9334 1859 Email: advocacy@nswcc.org.au

Cancer Voices is looking for ADMIN help

CVN is seeking to fill the following volunteer positions

- Database Manager – membership, newsletter and consumer reps lists
- Newsletter Formatting
- Website updating

These jobs support our operations and advocacy – they keep the wheels turning smoothly. They could well suit those who want to give something basic but prefer not to become involved in the advocacy side of things. Good clerical skills would be necessary. If interested in discussing further, please email us at info@cancervoices.org.au

STOP PRESS: As we go to print, we have received several excellent offers to help – THANKYOU!

CONSUMER INVOLVEMENT IN RESEARCH TRAINING 2014 – 29 & 30 August

This annual introduction to becoming a consumer advisor to cancer researchers will be held again in August. We encourage anyone interested in the direction and methods of cancer research, from epidemiology, “bench top” biology, treatments and psychosocial research , to consider signing up to the course.

Cancer researchers need your consumer perspective!

“Graduates” of the two day course can join our “match-making” database, through which we can offer you research projects where your advice will be highly valued.

Expressions of interest and exact dates can be found via www.cancercouncil.com.au/research/research-profile

Phone: (02) 9334 1445, Email: samth@nswcc.org.au

THANKS!

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

Contact CVN

PO Box 5016 Greenwich NSW 2065: E: info@cancervoices.org.au W: Website www.cancervoices.org.au

Your Committee met on 11 December 2013 and after the AGM on 12 February 2014. Much action goes on “out of session”, thanks to the joys of telecommunications! We meet again on 9 April

Annual General Meeting

Cancer Voices NSW’s Annual General Meeting was held on 12 February, followed by a short meeting for the 2014 Executive Committee and CVN members attending the AGM.

Committee and Office Bearers for 2014 are:

Chair: Sally Crossing
Deputy Chair: Elisabeth Kochman
Secretary (Minutes): Elisabeth Kochman
Treasurer (co-opted): Sandra O’Sullivan
Committee Members: Roberta Higginson, Bev Noble, Peter Brown, Bridget Whelan, Brian Lemin, Kathy Smith

Newsletter Editor: Sally Crossing
CIR Manager: Bridget Whelan

Kathy’s **Annual Report for 2013** is printed in this Newsletter. The 2012 Financial Statements were tabled and big thanks were conveyed to our Treasurer for preparing them. They have been reported to the NSW Office of Fair Trading, as required.

We welcome new Executive Committee member Brian Lemin. We farewell and thank Tony Maxwell for his valued contribution to CVN over the last few years. Tony continues as an experienced CVN consumer representative on a number of committees and research projects.

The Executive Committee also wants to publicly thank Barb Galvin for looking after our database and formatting this newsletter for the last two years. We are now looking for her replacement - see Noticeboard for details.

Bridget Whelan has kindly stepped up to take on the role of **Manager, Consumer Involvement in Research Program** – this involves responding to the ever increasing number of requests from cancer researchers for consumers to contribute to their reach projects. This is a free service developed by Cancer Voices, which has grown by 300% over the last year – we are delighted that Bridget has taken it on, as are the researchers needing our input! Thanks to Kathy Smith for managing this quite complex job for the last two years.

 **Award for Excellence in Cancer Consumer Advocacy 2014**

This Award, now in its third year, will be announced on 30 April at the Cancer Council NSW’s Research Awards presentation – always a well-attended and memorable event.

CVN’s Executive Committee has made its decision, which will be published in our June newsletter – we think our members will agree that it’s a very appropriate choice. We see the story of this very active cancer consumer advocate as an excellent example to others about how “big things from little things grow”

The first Award was made to Sally Hodgkinson and the second to Jane Barrett. Cancer Voices is delighted that the AWARD has become such a good showcase of volunteer consumer achievement.

Cancer Voices Website www.cancervoices.org.au

Our brand newly designed website is open for business. Do visit it at the usual address and tell us what you think. There is always more to do, particularly in the area of updating CVN’s Position Statements. CVN thanks Kerry Metcalfe who built and designed the website for us. She kindly continues to help us keep it up to date, a bit of a challenge for some of us less website literate.

CVN is looking for some help in loading new information, newsletters, media releases, submissions etc. and would love to hear from you if you could take on the mechanics, with editorial guidance of course.

New Cancer Voices leaflets – out now

Late last year we updated and reprinted 3000 two-fold leaflets for distribution. These are suitable for doctors’ and hospital waiting rooms, for gatherings of consumers, for support groups, conferences, and training courses – anywhere at all where for interested people affected by cancer.

The leaflet includes a Membership Application form for Cancer support and advocacy groups and for individuals. Being a part of the Cancer Voices family is such a good way to help others like ourselves – it costs nothing, is respected and is very effective.

Contact us via info@cancervoices.org.au or through the website if you would like us to send you multiples of

leaflet – or even one! We will insert a copy with this newsletter, which you might like to pass onto a friend

Members' Issues Survey

Thanks to those who filled in the insert which went with the December Newsletter, to pass on their ideas about what we should concentrate on advocacy-wise this year. This is always most helpful and appreciated. Don't wait until we ask you at year end – just email us any time, or send via the website. Your needs, ideas and views are what ensures we are doing is what people affected by cancer need!

CVN ADVOCACY UPDATES

NSW Cancer Statistics

Responding to concern that latest cancer incidence and mortality statistics are for 2008 – nearly six years out of date, CVN approached the Cancer Institute NSW for a formal explanation as to how this had come about, and its plans to restore relative currency to its published cancer data. We have been advised that the problem has occurred due to changed requirements of the Australian Bureau of Statistics. CVN continued to be concerned and suggests that the CINSW website provide estimates for the missing years in the interim, so that epidemiologists, service planners AND other consumers of this information can see a more up to date data sequence. The World Cancer Report, released early this year is able to provide estimates, so we will use them in the interim.

Coordination of Care

Cancer Voices has seen the need for a set of guidelines or similar to assist both clinical and patients toward best practice pathways in the coordination of care for cancer patients as a priority over the last few years. Cancer Voices has formally approached Cancer Australia, COSA's Cancer Care Coordination Group and the Cancer Institute NSW. Despite generally positive sounds, only recently has some action surfaced. On 7 Feb, one member of CVN was invited to the Cancer Institute NSW's full day addressing the issues and solutions – Peter Brown accepted the invitation for us.

Consumers attending cancer related conferences

This month, the Clinical Oncology Society of Australia (COSA) hosted a Care Coordination Conference in Sydney on 4 & 5 March, which did not offer registration free places to unsalaried consumers, so we were unable to attend. Neither, we understand, were other

volunteer cancer consumer groups, including the Cancer Council Australia's own new "in-house" advisory group. Cancer Voices, as the leading independent (no

pharma or government funding) cancer consumer group is rather concerned about the trend by previous practice and commitment, to include consumers as guests.

A few years ago, the accepted principal was that it was valuable for both health professionals and consumers to have the opportunity to exchange idea. Conferences also provide an opportunity for consumers to be brought up to date on new research achievements and directions. This opportunity now rarely arises. On the other hand, Cancer Voices is invited to all expenses paid conferences organised by the pharmaceutical industry, but to date we have been unable to accept their hospitality (travel, accommodation, conference, meals etc.), due to the fact that our doing so would reduce our reputation of independence. So this issue is quite a conundrum!

Medical Cannabis – slowly, slowly

Community concern about legal access to medical cannabis, in our case for symptom treatment (pain and nausea), has increased. As previously reported, there was widespread disappointment when the NSW Government decided not to accept the recommendations of the Legislative Councils' 2013 Inquiry. Cancer Voices took an active role in the Inquiry, supporting well safeguarded access for cancer patients. Since then, more American states have legalised access, bringing the total now to 20. Evidence that no harm is caused by allowing carefully controlled medical use continues to grow as more time passes and data is collected in so many other jurisdictions.

Cancer Surgery Waiting Times – What next?

Following our previous news that the National Health Performance Authority (NHPA) had released its report on cancer surgery waiting times, CVN asked the NSW Minister for Health what might be doable in NSW to assist the few "outlier" hospitals – those with waiting times of more than 30 days. We received a reply saying that the Cancer Institute NSW had suggesting that 30 days was not a benchmark, and that it was up to public hospitals to bring themselves up to standard.

CVN will now consider contacting the individual hospitals to ascertain whether their waiting times have improved since the data was collected, and ask about their plans to improve this aspect of their services. We had hoped that the Ministry itself would be more

interested in performance variations across the state. Another one for the growing 2014 agenda!

Clinical Practice Standards, please

Not much movement on this issue yet. CVN maintains that the adoption of Practice Standards for Radiation Oncology (which are well developed and available) and for Medical Oncology (yet to be developed) by state governments would be a welcome addition to the medical profession's armoury in best practice cancer treatment. Not to mention the potential improved outcomes for our cancer patients. There is in general principle support, but how best to implement without adding to cost burdens of administrators need to be resolved.

Security of Drug Supply

While the immediate problem of patient access to cyclophosphamide has been resolved (Baxter is now importing the 50mg tablets), the bigger issue of security of supply remains. Cancer Voices would like to see a regulator process which kicks in when supply is halted for whatever reason. To this end we have raised the issue with Medicines Australia's Oncology Taskforce, the National Cancer Expert Reference Group and MOGA.

Access to High Cost Cancer Drugs

Recognising the need for debate on the issue of how Australia can best approve and pay for increasingly costly and increasingly targeted (i.e. smaller markets) cancer drugs, we have engaged as best we can. Our Chair, Sally Crossing was interviewed by The Age newspaper for a feature article; Cancer Voices has made submissions and approached other concerned stakeholders.

Cancer Voices will participate in the Stakeholder Forum being organised for 26 and 27 March in Canberra by the Cancer Drugs Alliance, a group of Pharma and clinical interests. We see our most productive role as putting forward the informed, responsible consumer view. Do contact us if you would like to share yours with us.

Lymphoedema advocacy

Roberta Higginson (Chair BCAG NSW and CVN EC member) has been busy working with other involved groups and organisations about the best way to progress two aims:

- Medicare Item numbers for lymphoedema garments and treatment
- Adoption of guidelines at national and state levels regarding best practice lymphoedema treatment.

At this stage Cancer Voices has offered it's in principle support for alliance efforts towards the goals, waiting to

see details of the proposals and advice action plans. Both goals reflect our long term aims re a better deal for cancer patients and others having to cope with problems caused by lymphoedema.

Accommodation for travelling cancer patients

Cancer Voices wrote to the General Manager of the North Shore Local Health District about the limited accommodation options for people who need to travel to hospitals within the LHD, especially Royal North Shore Hospital. The problem has been exacerbated since Blue Gum Lodge in Greenwich closed its doors. Members have advised us that the new arrangements are still not meeting the needs of some travelling patients. We will keep this issue on the agenda. Are other areas experiencing similar problems?

Consumer Reps Programs

Consumer Advocacy Training courses – for 2014 new dates, please see Noticeboard on page 2.

Cancer Voices will continue to provide nominees to requesting policy and decision making organisations, as received via our website request forms.

Misconceptions about the roles of Consumer Reps

CVN still finds that a few (only a few these days) organisations are unwilling to accept that someone nominated by us will be more capable of putting a broad considered consumer view than an individual without a network and/or training. Some have transferred their concerns about industry and professional associations' representatives who are expected to speak FOR their own organisation, onto the idea of consumer representatives. This idea is completely misplaced and uninformed – and frankly, frustrating.

To us, and to most of our partners, it seems quite clear that health consumers nominated by their organisations are highly capable of adding value. Indeed the value of the informed, networked consumer is emphasised in the Cancer Australia's National Framework for Consumer Engagement (2011), now often quoted. We can only assume that there is a fear or control element involved – that our nominee may raise an issue that the organisation would prefer not to have aired. This seems a pretty unsophisticated attitude, if not contrary

to the whole principle of valid consumer views being offered to, and heard by, decision-makers.

Some still believe that our nominees speak for Cancer Voices the organisation. We have made clear in every Newsletter, that this is not the case – only designated CVN Office Bearers may do this, and then only very occasionally. We are not a trade union, industry or professional association sending out “our” organisational people to negotiate with them.

The point of consumer representatives is exactly that – representing the views and needs of people affected by cancer to the best of their ability. Please make this clear if your role is questioned in this way.

Consumer Involvement in Research

This year, CVN is looking to make changes to the extremely successful CIR “match-making” program, a free service for cancer researchers looking for an informed consumer to provide the consumer view to their projects. The object of these changes is largely to make training more relevant to the role of “consumer advisor” and their advice to researchers. The changes won’t affect the cancer researchers who so depend on our free service for linking them with capable consumers who are interested in and able to contribute the consumer perspective to research projects.

CVN has had discussions with the Cancer Council NSW, to see how they can assist with our supply/demand problems and to find solutions to reach a balance.

In 2013, there was a 300% increase in demand by cancer researchers. At the same time, the consumer supply side had dwindled, with few graduates of the annual Consumer Research Training course signing up to assist researchers in this way.

We warmly welcome Bridget Whelan, member of the CVN Executive and very experienced consumer rep in the research area, who has offered to take on the managing this service, at least for the rest of 2014, when we shall reevaluate operations.

CVN recognises that our match making service – freely provided over the last 8 years, has been very successful – a leader in Australia, and quite possibly beyond - and we continue to hope that it will eventually be taken on

by an appropriate and properly resourced organisation, like the Cancer Research Leaders’ Forum, with some kind of Cancer Voices oversight. We need to remind ourselves, and those we assist, that Cancer Voices is a consumer advocacy organisation, not a service provider!

In the meantime, we encourage any members who have not undertaken the Consumer Involvement in Research Training to do so in 2014. It will be held in Sydney in August – see Noticeboard (p2) for more details and on our website. It’s a great opportunity to have your say on cancer research and we really do need more trained consumers (both patients and carers) to help with the work.

Advising Cancer Research Institutes

CVN recognises that some Research Institutes prefer to engage with consumers they know and whom they have invited to join an “in-house” Consumer Advisory Panel (CAP). We also recognise the potential conflict that may arise by using this model, and that some funders question the validity of this kind of consumer engagement.

We believe the risk management issue can and must be addressed. We also strongly recommend that a one-day training program be offered to all potential CAP members, and that at least two CVN nominees be included to assist in the risk management aspect and provide practical advice from the experienced consumer viewpoint.

Kolling Medical Research Institute

CVN assisted the Kolling Medical Research Institute, located on the Royal North Shore Hospital campus, to develop and hold a successful training day for the 14 keen consumers who had expressed interest in joining their “in-house” panel. A further day of presentations and discussions about new Kolling projects has since been held.

Breast Cancer Special Interest Group, (Univ of Sydney Cancer Research Network). Cancer Voices members have been invited to speak about the role of consumers in the research process in 2013 and 2014. This year, Sally Crossing will give the opening address to about 100 attendees, on 12 March.

Macquarie University Hospital

CVN has been approached to advise the MUH Cancer Research team about how best to engage with consumers, looking at both our own “match-making” service and the option of an in-house Consumer Advisory panel.

Kinghorn Cancer Centre (KCC)

CVN continues to receive a number of requests for the KCC, although we understand they are also considering an "in-house" model.



The Voices being heard

Submissions

Feedback to MSAC on PET Scans for Breast Cancer (CVA)

Price Waterhouse Coopers: Review of 5PCA Medicine Management Programs

Cancer Australia: Guidance re Fear of Recurrence

Cancer Australia: Clinical guidance for responding to suffering in adults with cancer

Conferences /Seminars

Coordination of Care, Cancer Inst NSW, 7 Feb

COSA Care Coordination Conference 4/5 March- no support to attend regrettably

Media

The Age: High Cost of Cancer Drugs: SC interviewed and CVA Position Statement provided

Tribute to Ashleigh Moore AM – broadcast widely

Newcastle Herald – Medical cannabis

Partyline, National Rural Health Alliance

CVA News Update Feb. 2014 - broadcast widely

Presentations

Kolling Medical Research Institute, Training Day

Lynch Syndrome Open Forum, 15 Feb

Breast Cancer Special Interest Group USyd – Opening Address, 12 March.

WHAT'S HAPPENING AT STATE LEVEL?

Cancer Council NSW

Following news of internal reorganisation within the Cancer Council, CVN has booked a date for our next Joint Executives meeting in April. We very much appreciate the moral and practical support extended to us by the Cancer Council NSW, especially in those areas where our interests are mutual – which are many!

Cancer Institute NSW

While six CVN members serve on three CINSW Committees, there is currently little opportunity for real consumer engagement between CVN and CINSW. Communication has been seriously curtailed. We remain hopeful that this important government agency,

whose establishment and development we supported very actively, and with whom we worked closely over its first eight years, will make its current policy more inclusive again before long.

We are now awaiting the opportunity to comment on the CINSW's new Consumer Engagement Strategy, which has been developed internally by the CINSW. We are also keen to take up the roles allocated to us in the NSW Cancer Plan, developed by CINSW for the period 2011`-2015.

As 2014 Cancer Voices Chair, Sally Crossing has accepted Prof Currow's invitation to discuss issues, both for people affected by cancer in NSW, and how we can more productively work together as the peak generic cancer consumer organisation and the state's principal cancer agency. She will report on progress regarding a range of matters on our agenda in June Newsletter.

WHAT'S HAPPENING NATIONALLY?

Farewell to Ashleigh Moore (1958-2014)

The Cancer Voices family was deeply saddened by the loss of Ashleigh Moore OAM, Chair of Cancer Voices South Australia and a member of Cancer Voices Australia's Executive Committee. He was a valued friend and colleague with whom we had a long, warm and productive relationship.

A Tribute to Ashleigh, written by Julie Marker, appears on the CVA website under NEWS. His cancer consumer advocacy was extraordinarily successful and inspired hundreds of Cancer Voices SA members as well as the decision-makers he worked with, on behalf of people affected by cancer.

Cancer Voices received condolences from Cancer Australia, and many other organisations which appreciated his commitment and determination. He showed so many of us how and when to act up fearlessly for others like ourselves. Kathy Smith attended Ashleigh's funeral and contributed the following:

On Monday 3 February, 2014 Ashleigh Moore OAM, Founder and Chair of Cancer Voices South Australia and a member of the Executive Committee of Cancer Voices Australia finally, and sadly, lost his battle with cancer.

Ashleigh was first diagnosed with head and neck cancer in 2005 and following successful treatment went on to establish Cancer Voices SA in 2007. Ashleigh's dedication and hard work quickly saw CVSA become a force to be reckoned with and with Ashleigh's strong

dedication and doggedness for ethical, consumer centred focus within the health system he, and CVSA, were soon being consulted and listened to by stakeholders and decision makers in the cancer world at the state and national level.

In addition to advocacy through consumer rep roles and committees, and standing up as a lone voice representing almost 900 people affected by a radiotherapy underdosing incident, Ashleigh pioneered a new form of community awareness and engagement. Ashleigh was strong in his belief of a healthy eating and exercise regime as a pathway to good health and in 2009 Ashleigh established a Cancer Voices SA cycling team to take part in the "Tour Down Under" Community Challenge Ride. While he only needed five riders to form a team Ashleigh actually recruited 123, resulting in the setting of a new record for a community team in the history of the "Tour Down Under". Ashleigh soon came to the attention of the LIVESTRONG organisation and spoke at some of their events around the world. The LIVESTRONG community played a big role in Ashleigh's work and he was highly regarded by this valuable international organisation.

This also saw the membership of CVSA increase from 50 to in excess of 800 in a very short time. A fantastic team of cancer consumers raising a voice for the betterment of the cancer experience within the SA cancer community.

In 2010 Ashleigh was diagnosed with lung cancer, a diagnosis which, due to a flaw in the system had been delayed by several months. This event fired Ashleigh up as he realised that if this could happen to him, a savvy, active, system-aware person with previous experience of cancer and treatment, what could happen to someone not so educated and aware?

Ashleigh's achievements did not go unnoticed, and an Order of Australia Medal award was announced on Australia Day 2012, for exceptional service to the community through Cancer Voices SA.

Ashleigh's lung cancer returned in 2012 and he fought a hard battle to once more beat the disease. When cancer returned in mid-2013 most of us close to Ashleigh had come to think that maybe he was going to win again but it wasn't to be.

In the words of Julie Marker, Ashleigh's close friend and colleague and Deputy Chair at CVSA

"With ingenuity, style, wit, intelligence, warmth, integrity, clarity, tenacity, determination, persistence, strength the legacy from Ashleigh's Cancer Voices work is formidable and will continue to 'make a difference' for a long time ahead.

Many people get cancer, but few have 'raised a voice for people affected by cancer' so effectively as Ashleigh. This tribute is inadequate to fully express his legacy. Thank You Ashleigh Moore - An exceptional activist, a uniquely inspiring and amazing individual.

You are a hero to so many, a legend!, and it has been a privilege to have shared time with you".

DISCOVER-TT, Centre of research excellence

(Discovering Indigenous Strategies to Improve Cancer Outcomes Via Engagement, Research Translation and Training)

(Editor) We include this report from Kathy Smith to give you an idea of how Cancer Voices is working to find ways to improve the cancer joinery for Indigenous Australians.

DISCOVER-TT is funded by the National Health and Medical Research Council and is based at the Menzies School of Health Research in Brisbane and involves a partnership of people and organisations from across Australia and beyond and is part of the National Indigenous Cancer Network.

DISCOVER-TT was formed to address the marked disparities in cancer diagnosis, treatment and survival for Indigenous Australian cancer patients compared with other Australians diagnosed with cancer. The ultimate aim is to improve the survival and quality of life of indigenous people with cancer through a strategic focus on health system performance in the area of diagnosis, treatment and care.

Kathy Smith of Cancer Voices Australia (and CVN) is a member of the Advisory Board of DISCOVER-TT and is part of a team working on encouraging greater awareness of cancer through open community discussion in order to dispel myths, encourage participation in screening programs and bring an awareness of the necessity to fully complete treatment regimes.

Through community conversations it is envisaged that interest may be raised in people who feel they could advocate on behalf of their community. Advocacy training would be provided for such people and support for them to raise the voice of their community to be heard at stakeholder and decision maker level would be provided as requested or needed.

CVA sees this as an exciting and long overdue area of participation in order to encourage and empower Indigenous cancer consumers to work together to

improve cancer services and experiences for their communities.

National Breast Cancer Foundation's (NBCF) Report on Community Conversations (Feb 2014)

A number of Cancer Voices members, and members of other cancer consumer groups, attended these excellent "conversations" around Australia late last year.

The NBCF recognises that "Consumer & community consultation has significant potential to positively impact the way research is prioritised, commissioned, undertaken and used. It's also critical in ensuring that investments in research are relevant to, and reflective of, the needs of those affected by cancer, and their families".

The conversations put forward an extremely valuable set of research priorities and identified gaps. Many of these were not only breast cancer specific but applicable to all cancers. As a result, Cancer Voices warmly welcomes the NBCF Report, and will use it, together with its own publication *Towards meeting the research needs of Australian cancer consumers: Carla Saunders and Sally Crossing, BMC Research Notes 2012, 5:667*. We can take these priorities to cancer research funders, both government and charities, to provide consumer focus to the ongoing discussion about what consumers really think should be researched. We highly recommend our members getting hold of a copy- <http://www.nbcf.org.au/Research/Research-Achievements/Community-Conversations.aspx>

Cancer Voices NSW **ANNUAL REPORT 2013**

2013 was another busy year for Cancer Voices NSW (CVN). It is rewarding for all of us that as the new cancer centres settle into operation around NSW we are getting nothing but glowing reports about the services and staff. These centres would have to be one of best (if not the best) improvements for cancer consumers, both current and future, Australia has seen for many years. Making changes in any area of the cancer world is important but if patients don't have access to benefit from them the impact on cancer outcomes is much reduced. More patients than ever before can now access the benefits of diagnosis and treatment at modern, comprehensive facilities closer to their places of residence. Cancer Voices is proud to

have played a major advocacy role in achieving these changes.

Organisational

While general membership input and communication improved during 2013, the Executive Committee would still like to see more CVN members having a say in the direction of our activities, and in helping us pursue them.

Highlights

February saw us join Cancer Voices Australia to launch the "SAY NO TO GENE PATENTS" a petition and campaign, following the negative ruling in the case of Myriad's Australian patent of BRC1 gene. Despite much action here and overseas, and an Appeal in August, we are still waiting on the final decision.

The ongoing struggle for improved palliative care services in NSW continues with some positive results during the year, although there is a long way to go to meet the needs of palliative patients and their loved ones around the state.

CVN made a submission and an invited address to the NSW Senate Inquiry into the medical use of cannabis. While the recommendations of the Inquiry were positive, the NSW government remained unready to implement them. Cancer Voices continues to follow all options, including the development of a tablet form for TGA approval.

We continue to lobby the NSW Government concerning the "odd" way it classifies public chemotherapy patients as private patients receiving treatment in public hospitals – a practice which results in patients having to make copayments for their treatment. We are working to have the NSW government classify public patients as public thereby removing the copayment when being treated in public facilities.

In 2011 National Practice Standards for Radiation Oncology were developed and produced by the Royal Australian & New Zealand College of Radiology with consumer input. While these standards were adopted in Queensland, adoption by the NSW is proving slower. We will continue to work on this, and towards similar Practice Standards for medical oncology.

Consumer Representation: Nothing about us without us!

The end of December 2013 saw a total of 78 CVN nominated consumer representatives sitting on 183 committees of different types for 57 different

organisations. This does not include the literature reviewing activities for stakeholder organisations.

There are 93 individual research projects within 23 organisations for which CVN provides consumer input. All consumers nominated to work with decision-makers by CVN provide the broad consumer perspective; they are not expected to speak for Cancer Voices as an entity.

Success in the “match-making” part of CVN’s Consumer Involvement in Research Program has proved its worth. However operating it has become increasingly strained due to the number of requests and the paucity of trained willing consumers. As our efforts to find partners to assist with this process have come to nothing, the research cycle ending in March 2014 will be our last year of this service to researchers.

Consumer Training

Consumer Advocacy Training (CAT) courses were again held with CCNSW and their graduates invited to join Cancer Voices. A Consumer Involvement in Research (CIR) training course held in August was also well attended. CVN has been advising research institutions on establishing “in-house” Consumer Advisory Panels and their necessary training.

The Written Word

Quarterly 8-12 page newsletters were published during 2013 and mailed in hard copy as well as being posted on the website where they were searchable for reference/research purposes. Should more information be required on items mentioned in this Report, it can be found in the Newsletters.

Speaking Out

Members continued to attend many workshops, seminars, conferences, etc. during 2013. This is a very effective way to contribute the consumer view as well as an excellent way for attendees to remain current and knowledgeable in the cancer arena.

Electronic Communications

2013 saw CVN completely refresh and redesign its website. We invite feedback from members as to what

they like, as well as comment about what could be improved. Please visit at www.cancervoices.org.au

At December 2013, Cancer Voices members numbered 74 cancer support and advocacy groups (voting members, some of which have several hundred members), 346 individuals and 128 Associate and “for information” members. Our AGM will be held on 12 February 2014. We remain an entirely independent and voluntary organisation; our success depending on the efforts of members, consumer representatives and particularly, members of the Executive Committee.

Financial

The Treasurer’s Report for 2013 will be presented separately. The valuable volunteer work of members, of pro bono services such as newsletter printing and mailing by the Cancer Council NSW, help keep expenses down.

The 2013 Executive Committee met every two months at the CBD offices of UBS Investment Bank (also pro bono), and out of session as necessary. Members this year were Sally Crossing (Deputy Chair & Hon Sec), Sandra O’Sullivan (Co-opted Treasurer), Elisabeth Kochman, Bev Noble, Peter Brown, Tony Maxwell, Roberta Higginson, Bridget Whelan, Jan Mumford (co-opted), Kate Vines and Kathy Smith (Chair).

Reflection and Thanks

As CVN moves into another year, I would like to thank all our members for their encouragement and support. Thanks also go to the members of the Executive Committee for their work and attendance at meetings throughout the year and to all those who work in positions as consumers representatives in the “cancer world”. I have made the decision not to nominate for the Chair in 2014 but will make myself available to work with the Executive Team.

Thank you to our stakeholders and supporters who seek our views and work with our representatives. Together we can, and do, make a real difference.

KATHY SMITH, Chair

12 February 2014



PHOTOS PLEASE

We were a bit short of photos for this first quarter newsletter– please keep them coming in to humanise our green pages.



World Cancer Day, 4 February (www.worldcancerday.org)

World Cancer Day is a global initiative to raise awareness about cancer and encourage governments, organisations and individuals to rally to action. Cancer Voices Australia (CVA) is proud to be back working towards its aims and objectives on behalf of the cancer consumers of Australia. 2013 saw us fully engaged in providing the broad, networked, consumer view on national issues of Australians affected by cancer.

We look forward to continuing to work closely with all national cancer agencies and service providers to pursue further improvements to the cancer experience and its outcomes. We are delighted with the response to our invitation to consumer-governed cancer groups to work together on national generic issues on an "as needs", alliance basis. Such collaboration boosts the volume of the voices and ensures they are heard when and where they need to be.

Chemotherapy Funding Review

Extended interim funding arrangements for the dispensing of chemotherapy drugs (\$82m until 30 June 2015) were announced by Health Minister, Peter Dutton, in December. CVA has called for an efficient and transparent funding model to address the present complex and opaque arrangements under the Fifth Community Pharmacy Agreement (5PCA). We support Consumers Health Forum's (CHF) advice that negotiations should include stakeholders beyond government and industry.

Medical Oncology Practice Standards

Our call for development of clinical practice standards in medical oncology has been well received. To meet a demonstrated consumer and clinician need, this issue remains a priority on our advocacy program for 2014.

A Cancer Drugs Fund?

Initial discussions around the concept of an Australian version of the UK Cancer Drugs Fund are encouraging. CVA looks forward to offering the consumer perspective towards this and other proposals about how to ensure affordable and timely access to effective cancer drugs as the challenges increase.

Security of Cancer Drug Supply

CVA welcomes the news that Cyclophosphamide in 50mg tablet form is again available to fill the gap since Pfizer ceased supply on 1 October 2013. TGA has granted exemption from registration for Baxter's brand Endoxan which will be available from 1 February, 2014.

CVA remains concerned about the security of supply of necessary cancer drugs and the uncertainty which remains without supply assurance. Cancer patients want to see development of a policy which enables a speedy process to begin whenever cessation of supply is advised. We call for Government and industry, perhaps through the good offices of the TGA, and with consumer representation, to explore options so that this kind of situation won't occur again.

Cancer Surgery Waiting Times (See www.myhospitals.gov.au or <http://www.nhpa.gov.au>)

The National Health Performance Authority (NHPA)'s report and most recent data, covering all Australian hospitals, were released on 28 November 2013. Two CVA consumer representatives served on the advisory committee which contributed to the analysis and presentation of this vital data. The majority of hospitals met the 30 day waiting time criteria. We encourage our network groups to approach State Health Departments to ensure those hospitals which have difficulty meeting criteria are assisted to do so.

National Rural Health Alliance (NRHA)

Cancer Voices has accepted an invitation to become a Friend of the Alliance of the NRHA Inc, an important connection.

Cancer Voices is the independent, volunteer voice of Australians affected by cancer - since 2000



[Editor]: Cancer Voices Australia NEWS UPDATES are issued every two months, the next being April.



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 encourage, and to provide a facility for, those with experience of cancer to contribute to all levels of decision-making about the disease
- ✓ To define the issues that are important to cancer consumers and to advocate for 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 influence the direction of research into causes, prevention, optimal treatments and support
- ✓ To provide a forum for people affected by cancer to share experiences and information

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