Message to Members

We indicated in our last newsletter that another one would follow shortly as we still had so much more that we want to share with you – we did not want to disappoint! We have a lot to report at both national and state levels. Representation and participation has been strong at various stakeholder meetings, forums and events.

We have been working hard on our relationships with key stakeholders during the course of this year. Recently we have had productive discussions at a national level with Cancer Council Australia (CCA) and have contributed to their strategic plan. At a state level we continue our quarterly meetings with the Cancer Institute NSW.

We referred to the strong relationship with CVSA in our last newsletter and the collaboration on national matters. CV was represented by Chris Christensen, Chair CVSA, at the Consumer Health Forum Australia Ministerial Roundtable in Melbourne in August. See Chris’s report on Page 16.

**Consumer recognition with the creation of a new award by The Royal Australian and New Zealand College of Radiologists (RANZCR).** This new award is “to acknowledge outstanding commitment, passion and respect for consumers involved in health care advocacy”. RANZCR have named it **The Sally Crossing Award for Consumer Advocacy** in recognition of Sally’s “tireless effort and dedication”. For further details see P 3.

**Draft voluntary assisted dying bill:** a difficult (for some) and a very sensitive (for others) issue. CV has had very considered and measured discussions and in July, the Executive Committee decided to advocate for greater choice for people affected by cancer in relation to their treatment options.

An in-depth explanation regarding our position can be found on Page 5.

**Consumer Involvement in Research (CIR)** annual training day took place in September. The new training format has been used and positively received. We welcome new members who have joined following this course. It is a great way to contribute to cancer research in a meaningful way.

**Survivorship:** CV is delighted with the release of an updated **Survivorship Model** by the Clinical Oncology Society Australia (COSA) which now recognizes survivorship as being from diagnosis. Cancer Australia (CA) has released its **Principles of Cancer Survivorship** which provides a new national framework. CV has worked closely with both organisations on their respective projects. For full details of these releases see Page 8.

**Consumer advisory group in action:** The Australasian Gastro-Intestinal Trials Group (AGITG) Consumer Advisory Panel attended the AGITG 19th Annual Scientific Meeting held in Cairns on 4-6 October 2017. See Page 9 for an overview of this advisory group’s year.

We appreciate your support and feedback - it is always good to hear from you.

Best wishes to our readers, members and dedicated consumer representatives.

Elisabeth Kochman, Acting Chair and the Cancer Voices Executive Team

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October is our birthday month – CVN had its beginnings back in 2000.
**CVN Notice Board**

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**Consumer Advocacy Training – 2018**

**Connect with like-minded people and develop your advocacy skills.**

**Friday 4th and Saturday 5th May, 2018**

Courses are open to CVN and community members. Visit the Cancer Council’s website for dates and locations.

The two day 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**


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

**NB:** Mention you are a Cancer Voices member for automatic registration.

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**Cancer Voices AGM**

Notice for our 2018 AGM including date, venue and nomination forms will be in our December newsletter.

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**Cancer Voices SA**

For news from our colleagues in SA go to CVSA September Newsletter link:


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**THANKS to the Team who bring you this Newsletter:**

Kathryn Leaney for formatting, Sharon Pannewitz for database management and labels, Murray McLachlan for proof reading and Elisabeth Kochman as compiler & Editor & all our contributors.

We hope you find it interesting, even inspiring! Let us know about any other advocacy issues you think we should feature and/or work on, and if you would like to help.

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Cancer Voices NSW also greatly appreciates the assistance given by Cancer Council NSW (for this issue Jasmine Tobia & the packing team), for printing & posting Cancer Voices Newsletters.
Your Executive Committee met on 27 September at the offices of HCNSW. Robust discussion included our priority areas and the updates to our associated Position Statement (PS). As these are updated and endorsed by the EC they will put on the website and we will advise in the newsletter. Our new Palliative Care PS can be found on Page 4. Our draft Cancer Care Nurses PS is on Page 7.

We were delighted that EC member Sarah Lukeman was able to join us (by teleconference*) which enabled us to hear and discuss matters rural and regional. Issues highlighted by Sarah include equitable access to clinical trials (which is not covered by Isolated Patients Transport and Accommodation Scheme - IPTAAS) and a need to get clarity over “point to point” transport which may have inadvertently been affected by a recent State Government bill.

* To make it easy for as many of us to participate we have subscribed to a teleconference service. This service will also be invaluable for teleconferences between scheduled meetings. We thank HCNSW for the recommendation.

Celebration: Our longstanding EC member Bev Noble reached a significant milestone in September – 80 years young! Keep on “doing” Bev, it is keeping you young. You are an inspiration!

New Members
A warm welcome to those who have joined Cancer Voices in recent months. Please let us know if you would like to be more involved!

Consumer recognition with the creation of a new award by The Royal Australian and New Zealand College of Radiologists (RANZCR).

The RANZCR Sally Crossing Award for Consumer Advocacy

“To acknowledge outstanding commitment, passion and respect for consumers involved in health care advocacy. It is to be a prestigious honour only awarded on rare occasions for exceptional consumer contributions to radiation oncology, clinical radiology or related disciplines.

The award is named in honour of Ms Sally Crossing who was a passionate and well respected advocate for people affected by cancer over many years. Ms Crossing lost her battle with cancer in 2016 and the college would like to honour her memory by awarding the inaugural Sally Crossing Award for consumer advocacy posthumously to Ms Sally Crossing AM (1946-2016)”.

Peter Crossing AM, proudly accepted the award at the Annual Ceremony at the RANZCR ASM in Perth in October. This award is not only recognition of an individual, it is an acknowledgement that the consumer contribution is valued and respected. It validates and recognises both the contribution and participation of consumers and what we can and do bring to the “table” and how our combined commitment is about improving the lives of those affected by cancer.

Thank you RANZCR for this recognition.

Note: We will have more on the broader aspects of the conference in our December newsletter.
CVN Advocacy Updates

Lymphoedema Action for NSW

The Lymphoedema Action Alliance (LAA) (of which CVN is a member) had its fourth meeting for 2017 on 17 October.

LAA is seeking a meeting with Hon. Brad Hazzard MP, NSW Minister for Health and Minister for Medical Research. Since our last meeting, the LAA has been updating and preparing documentation in readiness for this meeting.

We reported in our previous newsletter that LAA South Australian colleagues had had a positive meeting with the SA Government. They are still waiting to hear back from Government.

Insurance for people affected by cancer – progress update

A lot of work has taken place since the survey of insurance issues affecting people with serious health issues closed. A report based on the survey findings is now in draft form and is still subject to a review process and editing. We await the release and availability of the report and will advise accordingly.

Palliative Care Update

Following the detailed reporting by Murray McLachlan in our last newsletter we are still waiting on the report of the roundtable meetings held earlier this year. We understand that the report has been finished and is going through the government approval processes. We will advise when available.

At our July EC meeting, the committee endorsed the following position statement which sets out the background to the issue, the aim of our involvement, the objectives and strategies along with actions to be pursued and the key relationships that CVN will use to bring about improved palliative care services.

PALLIATIVE CARE POSITION STATEMENT - July 2017

BACKGROUND

Efforts to improve the provision of palliative care services are vital to both cancer patients and their carers/families, to help ensure that these services are both timely and targeted.

Cancer Voices NSW continues to be concerned that NSW remains below national standards, in particular in relation to the allocation of workforce resources, and the variable levels of these resources across the state and between, and within, metropolitan and rural/regional locations.

AIM

To contribute to the improvement of palliative and end-of-life care services across the whole of NSW to ensure they are readily available to people with cancer at the time that they need them.

OBJECTIVES/STRATEGIES

I. influence decision making by the NSW Government about improving integrated end-of-life and palliative care in an equitable manner across the state

II. influence the education, training, and access to information, of palliative care providers

III. where appropriate, facilitate consumer participation in research about palliative care service provision and the development and review of NSW palliative care-related information resources

IV. work with, and support, the work of other palliative care advocates in the introduction and improvement of palliative care services

V. when and where appropriate, contribute to the debate on voluntary assisted dying in NSW

ACTIONS

- Provide input to NSW Government policy development and decision making regarding palliative care, including the development by the NSW Agency for Clinical Innovation of a ‘strategic intent’ document to supplement and support the current framework document Palliative and End-of-Life Care: a blueprint for improvement.

- Meet with decision makers and influencers within government and the health bureaucracy to present specific issues regarding cancer-related palliative and end-of-life care services.

- Identify areas for improvement in the initial education and ongoing training of palliative care providers, and access to information of families and friends, to help ensure it is appropriately focused and up to date.
• Identify opportunities to include a cancer consumer perspective in research about the need for palliative care.
• Meet on a regular basis with palliative care-related organisations, and other palliative care advocates, to support their work in improving services on a state wide and local basis.
• Contribute to the debate on voluntary assisted dying, from a cancer consumer perspective, in NSW and other states as it may affect NSW.

KEY RELATIONSHIPS
• Minister for Health; Shadow Minister for Health
• Ministry of Health/Health and Social Policy Branch
• Agency for Clinical Innovation Palliative Care Network
• palliative care education and training accrediting institutions
• palliative care providers’ professional bodies
• voluntary palliative care provider networks
• Palliative Care NSW
• Cancer Council NSW (Palliative Care campaign)
• Push for Palliative (Yvonne McMaster)

Version as at: approved at Executive Committee meeting, 13 July 2017.

Palliative Care - Consumer Representation
It is pleasing to report, as the Consumer Representative on the Government funded Medical Cannabis Trial, to evaluate whether a vaporised cannabis product will assist in the quality of life for terminally ill adult patients. The trial is currently taking place at one Sydney Hospital and one Newcastle Hospital and the team is looking forward to the results which will be advised in due course. This has been a long and involved process with the hope that Cannabis will have a valuable place in relieving some of the pain and suffering of many Cancer Palliative Patients.

Thank you to Professor Agar and her team.

The University of Technology Sydney is also involved in research to improve outcomes for people in the last year of life which involves breathlessness, delirium and pain management. Cancer Voices is part of the Consumer Team and as such, look forward to improved management of end of life care.

The University of Technology Centre for Cardiovascular and Chronic Care has established a Consumer Advisory Group looking at many aspects of Chronic and End of Life Care with a number of consumer representatives. Cancer Voices “has a seat at the table”.

Bev Noble

CareSearch – for Palliative Care Information. Website: www.caresearch.com.au
CareSearch is a Commonwealth funded evidence based website providing information for anyone providing palliative care and anyone affected by the need for palliative care whether a patient, carer, family member or member of the community.

CareSearch are currently undertaking a survey (*) aimed at the Australian public to find out their views on death and dying, their awareness of palliative care and of CareSearch; and of how they find and use online health information. (*) Please consider taking the survey. Further information on the survey can be found on the CareSearch website: https://www.caresearch.com.au/caresearch/tabid/4234/Default.aspx

Cancer Voices NSW takes a stand on voluntary assisted dying legislation
Many attempts have been made to introduce ‘voluntary assisted dying’ legislation (or ‘euthanasia’) in different Australian states and territories over a number of decades. All have been unsuccessful, or where successful, in the Northern Territory and the Australian Capital Territory, were made invalid by the passage of overriding legislation by the federal parliament.

In New South Wales, a Parliamentary Working Group on Assisted Dying has worked from 2015 to 2017, through wide community consultation, to develop the Voluntary Assisted Dying Bill 2017 which was presented to the NSW Legislative Council on 21 September 2017. It is expected that debate on the bill will take place during November 2017, after the consideration of similar legislation by the Victorian parliament.

The legislation resulted from the combined efforts of upper and lower house members from the Nationals, the Greens, the Labor Party, the Liberal Party, and an independent as members of the parliamentary working group.
Cancer Voices NSW had not previously had an organisational position on voluntary assisted dying (or the other terms such as euthanasia that have been used in the past) until the Executive Committee decided in July 2017 to advocate for greater choice for people with cancer in relation to their treatment options. Prior to this, it was always made clear that any opinion expressed by an individual connected to CVN was a personal one.

In July 2017, the Executive Committee endorsed a submission to the Parliamentary Working Group as a means of contributing to the debate in NSW, which it is hoped will lead to the passage of legislation that will provide a choice to those dying from cancer to make use of provisions for ending their life.

The submission emphasised that adequate and timely palliative and end-of-life care remains central to the optimisation of cancer treatment and care to cancer patients, as vital elements in helping to ensure their well-being. In that regard, Cancer Voices indicated its strong commitment to palliative care as detailed in the NSW Cancer Plan developed by Cancer Institute of NSW. Further, the submission indicated that Cancer Voices NSW has welcomed the recent recognition by the NSW Government of the importance of palliative care through an allocation of $100million expenditure over four years on improved palliative care resources and training.

Central to the submission was the indication that the reality of many cancer diagnoses and subsequent disease progression is that a patient’s needs can only be met through end-of-life care, that is, the support for people who are in their last weeks or days of life. It is during these ‘end stages’ that the range of options of care become increasingly limited, a time at which many dying patients are increasingly unable to determine, or even influence, their level of care. This is inconsistent with the cultural shift that is taking place in medicine whereby the doctor-patient relationship is becoming less one-sided on the doctor’s part, allowing the patient greater input to decisions that affect their health and well-being.

It is at this end stage that patients whose life expectancy is limited should have, as one of a range of options, the right to end their life at a time of their choosing. In this regard, the draft bill has adopted a considered and sound approach to patient-doctor cooperation. The submission noted the safeguards of the proposed arrangements, including that ‘a patient must be provided information by their primary medical practitioner relating to the medical treatment, including palliative care, counselling and psychiatric support and measures for keeping the patient alive, that might be available to the patient’.

As an organisation that advocates for the rights of people affected by cancer, Cancer Voices NSW has taken the policy position on the draft bill that is supportive of those who want to make the choice as to how their lives will end, and through this to help ensure that the patient is at the centre of any process that is in place regarding such decision making.

In relation to the specifics of the draft legislation, Cancer Voices indicated its support for the requirements that, in order to receive assistance, eligible patients must be assessed by: a primary medical practitioner; a secondary medical practitioner (who must be a specialist), and an independent qualified psychiatrist or psychologist (to confirm the patient is of sound mind, has decision-making capacity, and is making their decision freely and voluntarily and after due consideration), which, when combined with elements such as a 48-hour ‘cooling off’ period, are suitably rigorous.

The submission pointed out that there are potential equity and access issues in relation to these requirements in that there are significant geographic areas in New South Wales that are remote and isolated, and where there may not be sufficient medical personnel available to make the assessment of people, or where ready access to medical personnel is difficult.

The ‘eligibility’ provisions in the draft bill, whereby a person wanting to exercise their right to assisted dying must be: at least 25 years of age and ordinarily resident in New South Wales, suffering from a terminal illness which in reasonable medical judgement will result in the death of the patient within 12 months, and experiencing severe pain, suffering or physical incapacity to an extent deemed unacceptable to the patient, were also seen to be suitably rigorous.

Cancer Voices NSW noted the requirement that a patient must be 25 years of age, and pointed out that significant numbers of people with cancer, and who die as a result of their disease, are aged between 18 (the accepted age of adulthood) and 25, which means that younger patients who are able to make autonomous decisions about every other aspect of their lives would be unable to make use of the proposed voluntary assisted dying provisions.
The Executive Committee has identified the need for ongoing involvement in, and advocacy for, assisted dying legislation, including through:

- meeting with decision makers and influencers within government to present specific issues regarding the need for enhanced choice for people with cancer in relation to voluntary assisted dying
- identifying opportunities to include a cancer consumer perspective in research about the need for voluntary assisted dying legislation
- meeting with appropriate organisations to support their work in furthering the debate on, and achievement of, improved patient choice in relation to voluntary assisted dying
- monitoring progress on the passage of voluntary assisted dying legislation in NSW and other states
- contributing to the debate on voluntary assisted dying from a cancer consumer perspective, in NSW and other states as it may affect NSW.

Murray McLachlan

Cancer Nurse Coordinators

Many more are needed. We heard on 13 October in a media interview for an event for Metastatic Breast Cancer in Sydney that there are only six metastatic breast care nurses in Australia!

In the interest of equity, CV is asking that newly funded positions be made generic, or at least transferable.

Following is the draft of our new position statement regarding Cancer Nurse Coordinators which states the background to the issue, the aim, the objectives and strategies, key relationships that will be used to improve the number of and access to this value and vital support.

CANCER NURSE CARE COORDINATORS POSITION STATEMENT August 2017

BACKGROUND

Specialist cancer nurses (cancer care coordinators) are good system navigators for cancer patients and their carers. Their role creates efficiencies in the system by freeing up other specialists and reducing the stress of self-navigation through cancer treatment. While there have been a number of private and private/public models to provide specialist nurses for the common cancers, it would be in the interests of equity for all Australian cancer patients if new funded positions were generic, or at least transferable. This would offer interested nurses a more attractive career path across more cancers.

AIM

To ensure equitable access to specialist cancer nurses/care coordinators regardless of their cancer type, geographic location and type of health system (private/public).

OBJECTIVES/STRATEGIES

I. Influence decision making by the Commonwealth and NSW Government about improving access to care coordination in an equitable manner across the jurisdictions.

II. Facilitate consumer participation in the development of models to provide specialist cancer nurses.

III. Influence the education, training, and access to information, of care coordination service providers.

IV. Work with, and support, the work of other cancer advocates in the introduction and improvement of cancer care coordinator services.

V. When and where appropriate, contribute to the debate on the provision of cancer care coordination services and the development of models of care.

ACTIONS

- Monitor and contribute to the debate on the need for specialist cancer care nurses, from a cancer consumer perspective, in NSW and other states.
- Meet with decision makers and influencers within government and the health bureaucracy to present specific issues regarding specialist cancer nurses.
- Identify cancer advocacy groups prepared to develop models of care.
- Meet on a regular basis with existing specialist cancer nurse care-related organisations, and other cancer nurse advocates, to support their work in advocating for specialist cancer nurse services.

KEY RELATIONSHIPS

- Government
  - Commonwealth Minister for Health; Shadow Minister for Health
  - State equivalents
- Health Professional Associations
  - NSW Oncology Group Neuro-Oncology
Access to high cost drugs

It was announced in October that the Cancer Drugs Alliance (CDA) is to cease operations and its Cancer Drugs Access Committee (CDAC) merged into Rare Cancers Australia (RCA). Richard Vines, Chair of RCA, was also Co-Chair of CDAC with Prof John Zalcberg. It was realised that there was overlap between the two organisations and that a merging would provide management and resourcing efficiencies. It is believed that the higher profile of RCA will be a better vehicle for this important work – that of the timely access to affordable cancer drugs for cancer patients. Prof John Zalcberg will continue to work with Richard Vines. CVA and CVN are very supportive of this work.

Survivorship

CV is delighted that we now have survivorship recognised from diagnosis by COSA through its updated Survivorship Model. We also welcome the new national framework from Cancer Australia. CV has worked closely with both organisations on their respective projects.

COSA survivorship model – revised

COSA released its earlier Survivorship Model in 2016. That initial model only addressed survivorship from “the end of active treatment” despite acknowledging that the international definition defines survivorship as being from diagnosis. As we know, treatment does not end for many who are diagnosed with cancer.

In June this year, COSA released an updated Survivorship Model which now acknowledges survivorship as being from diagnosis. Issues such as needs assessment, care plans and rehabilitation are now discussed during treatment.


(Thanks to reps from CVN and CVSA regarding the 2016 release - in particular, we would like to acknowledge the input of Chris Christensen from CVSA)

Cancer Australia (CA): Principles of Cancer Survivorship

In March 2016, we reported that CA had begun work on the development of a national framework for the principles of Survivorship. Stakeholder consultations took place in June 2016. The late Sally Crossing AM and Dan Kent represented CVA and the Australian Cancer Consumer Network (ACCN) respectively.

CA released the new national framework in August this year which comprises of five key principles:

- consumer involvement in person-centred care
- support for living well
- evidence based care pathways
- coordinated and integrated care
- data-driven improvements and investment in research

The following is an extract from the Cancer Australia website (14/08/2017):

Cancer Australia today released the Principles of Cancer Survivorship, which provide a national framework to guide policy, planning and health system responses to cancer survivorship, focusing on the health and wellbeing of people living with and beyond cancer.

Cancer Australia CEO, Dr Helen Zorbas, said that Australia has among the highest cancer survival rates in the world.

“Due to improvements in diagnosis, earlier detection and advances in treatment, more Australians are surviving cancer than ever before. An estimated 1.1 million people living in Australia have had a diagnosis of cancer*,” said Dr Zorbas.
“With the number of cancer diagnoses projected to increase by nearly 40% between 2015 and 2025, there is an ongoing need to address the long-term health and wellbeing of people affected by cancer.

“Cancer Australia has developed the Principles of Cancer Survivorship to guide planning and health system responses which better support people to live well after cancer,” Dr Zorbas said.

The Principles are supported by intended outcomes and underpinned by elements to achieve personalised care, opportunities for self-management and an emphasis on recognising and incorporating patient experiences. The Principles focus on patients’ ongoing management, recovery, health and wellbeing during and after cancer treatment.

Development of the Principles was undertaken through a process of consultation and engagement with national leaders in survivorship care, including people affected by cancer.

The Principles are designed to complement and support existing activities in survivorship and underpin national approaches to evidence-based high quality cancer survivorship across the continuum of care.


CanForum 2017 Parliament House Canberra

On 9 August 2017, I attended CanForum 2017 as the representative from Cancer Voices NSW. Thank you for the opportunity.

This was the most successful Parliamentary event that I have attended, under the auspices of Rare Cancers Australia (RCA). There were some 150 attendees including patients and their families, clinicians, industry, health economists and Government.

The focus of the event and media in the run up to CanForum was the new report by RCA – Rare Solutions – A time to Act. It was prepared by PWC and acknowledged AstraZeneca as the principal sponsor along with eleven other big pharma companies.

The key recommendations of the report are around local clinical trials, subsided access and collaboration. It includes a focus on the opportunities and challenges of genomic medicine.

The Minister for Health, Greg Hunt, gave a keynote address that was very encouraging. He seems to have a good grasp of emerging treatment, the issues and showed an understanding of the challenges.

The key talking point for the Government at present is that “medical research is one of the four pillars of the Turnbull Government’s Long Term National Health Plan. And our commitment to the Medical Research Future Fund will see our direct funding for health and medical research effectively double by 2021.”

The event was compared by Sophie Scott, National Medical Reporter for the ABC and an ambassador for bowel cancer. It was also a great networking opportunity.

Further details about this event can be found at https://www.rarecancers.org.au/news/category/117/past-events


Susan Pitt

Consumer advisory group in action

The Australasian Gastro-Intestinal Trials Group (AGITG) Consumer Advisory Panel attended the AGITG 19th Annual Scientific Meeting held in Cairns on 4-6 October 2017. The Panel has a broad range of goals in providing the community perspective - reviewing research concepts and patient information and consent forms, participating in the Working Parties that develop research, involvement in selection committees for awards and grants and planning and presenting at the annual meeting.

This year saw a 50% changeover of consumers on the Panel. While it is sad to have ‘lost’ familiar faces (due to their tenure been finished, or were unable to continue), the selection was tough. The cancer health consumer space has matured and this was evident by the quality
and experience of the applicants in the consumer roles. Some of the diverse skills brought to the Panel include one of the members with business interests who has volunteered time to help the board with the mission and vision rewrite. Another member (retired) who has followed cell work and genomics closely has been offered time in a lab to test his theories and it has been suggested he do a PhD. Another member has come up through the ranks, so to speak, working with Canteen; one member is retired and has worked extensively with his state’s health department and now looks at policy differently, and one member works as an Occupational Therapist, with experience as their partner participated in a trial and from this has a very clear consumer focus.

This year the Panel had two posters accepted for the Annual Scientific Meeting, a new activity for Panel members. One poster was on Optimum Care Pathways and the other on Mobile Phone or Tablet Apps for Clinical Trials. There was interest from the health professional delegates in both topics. We are looking forward to doing this again next year to highlight the community perspective and needs at this highly regarded scientific meeting. **Jan Mumford**

Please contact us if you would like an electronic copy of these posters at info@cancervoices.org.au

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**Garvan Launch – Genomic Cancer Medicine Program**

Bev Noble and Elisabeth Kochman attended the launch of the Garvan’s Genomic Cancer Medicine Program on 23 August. We were more than impressed by those who spoke so openly, honestly and passionately about this exciting program and direction in cancer research and cancer treatment. This program was officially launched by the Hon. Brad Hazzard MP, NSW Minister for Health and Minister for Medical Research who had both a good understanding and showed genuine support for this initiative. Certainly exciting times for all involved. For further details:


**Royal Australian College of General Practitioners (RACGPs)**

Prof Ken Hillman gave the Charles Webb Bridge Oration on 30 August entitled *medicalization of dying*. This was based on his recent book *A Good Life to the End*.

Ken Hillman is a Professor of intensive care at UNSW. In his book he talks about over treatment and too many interventions on our elderly when what they really want to do is die peacefully at home with loved ones. For more information:


Ken Hillman was also interviewed on the ABC Conversation Hour with Chris Fidler on 22 August. That conversation was entitled “*The cost of denying death*”. To hear that interview, follow the link below:


**Elisabeth Kochman**

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**Consumer Reps Program**

Cancer Voices continues to provide nominees on request by stakeholders, via our website Request a Consumer Representative form. We make it clear that those nominees are informed and are there to represent the broad view of people affected by cancer – not of the organisation itself, or of an individual alone. These requests are usually made by cancer professional organisations, government agencies and health service planners.

**Training:** Please check the Noticeboard for information about the next Consumer Advocacy Training (CAT) course to be held by the Cancer Council NSW in May 2018. Cancer Voices welcomes new members who have completed a CAT course this year, and looks forward to introducing them to our activities, advocacy and research programs, as well as hearing their ideas about issues for people affected by cancer. – See Noticeboard Page 2 for details.
Consumer Involvement in Research (CIR)

The 2017 training of consumers for our consumers in research program took place on Friday 22 September at the Cancer Council NSW. There were ten consumers who undertook the course and who are now part of our CIR database. All were highly motivated and will bring a range of talents to CIR. The conversations were highly engaging and benefited the new recruits.

The new course comprises four online modules (available on the Cancer Council Australia website). It is a prerequisite to complete the online modules prior to attending a half day face to face workshop/presentation day. This new course structure has proved to be a successful format and beneficial to the CIR program.

Our thanks once again to CCNSW for the ongoing partnering in this valued program.

We are in a shoulder period of the research cycle at present where requests are low. We are approaching that time of the cycle where the number of researchers requesting consumers for their projects really increases. December to March is an intense few months of matching suitable consumers to those research requests.

Lee Hunt

Focus on Metastatic Breast Cancer

EC member Elaine George championed the inaugural Flashmob Dance Event in Martin Place, Sydney on 13 October to put a focus on metastatic breast cancer. This event was sponsored by the Breast Cancer Network Australia (BCNA), the McGrath Foundation and Fitness First.

Below are links to access interviews held on the day:

Interview Elaine George on metastatic breast cancer - YouTube
https://www.youtube.com/watch?v=1F1gHEKIGN0

Metastatic breast cancer awareness flash mob dance - YouTube
(KEY HIGHLIGHTS from the event - showing the dancing!) https://www.youtube.com/watch?v=_tvxTUr8bJs

Contact CVN: We hope that you have noted our changed our mailing address (advised in our last newsletters). Please update your records if you haven't already done so.
PO Box 713 Milsons Point NSW 1565: E: info@cancervoices.org.au
W: www.cancervoices.org.au
The Voices being heard

Meetings

- Cancer Voices SA, 21 August (telecon)
- Cancer Council Aust, 22 August (telecon)
- CVN / CVSA 29 August (telecon)
- Cancer Institute NSW, quarterly meeting, 31 August (telecon)
- Health Consumers NSW, EGM, 21 September (telecon)
- RANZCR M & P Committee, 27 September
- Centre for Community Driven Research, 27 September (telecon)
- Medicines Australia, 4 October (telecon)
- Cancer Institute NSW, incl David Currow, 5 October
- FRO Council, 13 October
- Lymphoedema Action Alliance, 17 October
- Menzies School of Health Research, various
- UTS, Aug-Oct (various / ongoing)

Submissions

- MSAC application request for letter of support re hereditary colorectal and endometrial cancer genetic testing, July (CVA led by CVSA)

Conferences / Forums/ Events

- Senate Inquiry on Availability & Accessibility of Diagnostic Equipment around Aust, Sept (CVA)

The Financial Cost of Breast Cancer

The Breast Cancer Network Australia (BCNA) has surveyed around 2,000 members about the financial consequences of their breast cancer diagnosis for both themselves and their families. The report highlights the disparity across Australia in the out-of-pocket costs women face following a breast cancer diagnosis. The 35 page report is available at https://www.bcna.org.au/media/5609/the-financial-impact-of-breast-cancer.pdf

Name Change - The Australian and New Zealand Breast Cancer Trials Group (ANZBCTG) is excited to announce its new name and new website details:

“Our new name is Breast Cancer Trials and our new website is located at www.breastcancertrials.org.au.

After 40 years of research achievements that have improved treatments, changed practice and saved lives, it was time to bring our research activities under the ANZBCTG and our fundraising activities under the Breast Cancer Institute of Australia, together under one name. Breast Cancer Trials represents who we are today – a unique collaboration between our members and researchers, clinical trial participants and our supporters.

The new name Breast Cancer Trials clearly defines what we do and the research we conduct, and highlights our unique point of difference to other breast cancer charities and research organisations. Our logo recognises our place in the world, with a map of Australia and New Zealand, and resembles a fingerprint which speaks to the tailoring of breast cancer treatments to every individual and their unique set of circumstances.

So while our name has changed, our commitment to collaborative, high quality breast cancer clinical trials research has not. We are still the same group of world-class professionals based in Australia and New Zealand on a mission for people affected by breast cancer to live better, to live longer, and to never die from breast cancer”.

For further assistance, please don’t hesitate to contact enquiries@bctrials.org.au.
Cancer Council NSW Update

Curious about Immunotherapy?
Over the last few years, immunotherapy drugs that stimulate the body’s own immune system to fight cancer have received a lot of media attention and have sometimes been described as “miracle drugs”.

Cancer Council’s new online fact sheet Understanding Immunotherapy provides an introduction to the type of immunotherapy currently available in Australia, called checkpoint inhibitors. It includes information on what immunotherapy is, how it works, types of immunotherapy, how it is given, the challenges of using this treatment, and managing side effects.

The fact sheet is available in PDF form and can be downloaded from cancercouncil.com.au/publications, or you can read it online at cancercouncil.com.au/cancer-information/cancer-treatment/immunotherapy.

You can also listen to the Cancer Council podcast about New Cancer Treatments – Immunotherapy and Targeted Therapy, which features medical oncologist Dr Steven Kao from Chris O’Brien Lifehouse. Dr Kao explains how these treatments differ from chemotherapy, and what advances have been made in these newer treatments in recent years. He discusses checkpoint inhibitors such as Keytruda and Opdivo, as well as talking about the practical side of how the drugs are administered, and the side effects people may experience.

The podcast is available at cancercouncil.com.au/podcasts and through iTunes.

New Cancer Council information podcast series – The Thing About Cancer
Cancer Council NSW has recently launched an innovative new information podcast series, called The Thing About Cancer. The series of 10 podcasts explores topics that resonate with many people affected by a cancer diagnosis, including coping with a diagnosis, making treatment decisions, managing side effects, and how cancer affects carers.

The series is hosted by renowned radio broadcaster and cancer survivor, Julie McCrossin, and each podcast is presented in an interview style format featuring expert guests, such as oncologists, psychologists and researchers. The personal experiences of people affected by cancer are also reflected in many of the episodes.

Podcasts are an increasingly popular and convenient way to consume information. They can be live streamed, or downloaded to smartphones and other devices, enabling people to listen when and where they choose – in the car, sitting in a chemotherapy chair, walking the dog or lying in bed.

The information in the podcasts complements Cancer Council’s existing printed Understanding Cancer information resources and episodes include:

- Coping with a cancer diagnosis
- Cancer affects the carer too
- Making treatment decisions
- Managing cancer fatigue
- Sex and cancer
- How to help someone with cancer
- Explaining cancer to kids
- Appetite loss and nausea
- New cancer treatments: immunotherapy and targeted therapy
- Genetic tests and cancer

The podcasts are free and available now at cancercouncil.com.au/podcasts or via iTunes.

For more information about the series and the available episodes, please visit cancercouncil.com.au/podcasts.
Cancer Institute NSW Update

The Cancer Institute NSW held its 6th Innovations in Cancer Treatment and Care Conference on 14 September 2017. To view the program and videos of this very informative day visit


Note: We will have more from CINSW in our next newsletter.

Health Informatics Society of Aust (HISA) Breakfast 10 October with Dave deBronkart - aka e-Patient Dave

Dave deBronkart is the best known advocate in the US for the patient engagement movement. Known on the internet as e-Patient Dave, he is an accomplished speaker and author of "Let Patients Help: A Patient Engagement Handbook."

After beating stage IV kidney cancer in 2007 Dave deBronkart became a blogger, health policy advisor and international keynote speaker. Dave’s TED Talk Let Patients Help went viral, and for years was in the top half of the most viewed TED Talks of all time. He is recognised in the US as the best-known spokesman for the patient engagement movement, attending over 500 conferences and policy meetings in 15 countries, including testifying in Washington for patient access to the medical record under Meaningful Use.

As co-founder and chair emeritus of the Society for Participatory Medicine, e-Patient Dave has been published in the British Medical Journal, the Society for General Internal Medicine Forum, iHealthBeat, and the conference journal of the American Society for Clinical Oncology.

For further information: http://www.epatientdave.com/
REINVENTED: Alana Henderson has found a new lease on life since taking charge of her recovery from a number of health setbacks including stroke, breast cancer, diabetes and weight problems.

Alana Henderson, author, was an attendee at the Health Informatics Society of Aust (HISA) Breakfast with Dave deBronkart.

In her memoir, *Out of the Fog: Adventures through Lifestyle Change* (2016), Ms Henderson also describes how she took charge of her recovery from the major illnesses to build a confident, healthy, exciting and quality life.

“The book challenges [health professionals] to apply best practice and creativity rather than limiting their knowledge in day-to-day work tasks,” Henderson said.


In ‘Enactus UNSW’. We are a community of students, academic and business leaders committed to using the power of entrepreneurial action to develop social enterprise projects that are able to empower the community. In particular, one of the initiatives that we are currently working on a project called open Door Learning’.

The aim of our project is to provide educational support to patients who have been affected by chronic illnesses such as cancer, renal disease or gastrointestinal conditions. The service will be free for our beneficiaries (students from year 5 to year 12) and we are looking to hold the service once a week. Our tutors are available for assistance in all primary and high school subjects. As such, we are aiming to provide a tailored service to each individual in an attempt to encourage each student to achieve their academic and personal potential.

**Triple Test for breast cancer**

Cancer Australia ‘Triple test’ guide for GPs maximises accuracy of breast cancer diagnosis

Cancer Australia has released a guide for GPs designed to maximise the effectiveness of the investigation of symptoms that could be breast cancer.

*The investigation of a new breast symptom: a guide for General Practitioners* details the triple test, which is the recommended approach to investigating new breast symptoms. The triple test involves patient history and clinical breast examination; mammography and/or ultrasound imaging; and the use of non-excisional biopsy. When performed appropriately, the triple test will detect over 99.6% of breast cancers.

Consumers Included “seal of approval”: The added value and benefit of including informed consumers in cancer conferences, forums and other events, for the organiser, the attendees, representative consumers and their networks, has been demonstrated and is now well accepted. To promote and encourage this practice, a “seal of approval” logo was developed and is now available for use. This Cancer Voices initiative continues to attract interest.

The approved organisations are listed on the CI website and details can be found at http://www.cancervoiceaustralia.org/consumers-included/ and http://consumersincluded.wordpress.com/.

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

Cancer Voices representation at the Consumer Health Forum Australia (CHF Aust) Ministerial Roundtable 23 August 2017

I was most fortunate to be one of twenty health consumers from around Australia who met with Minister Hunt in Melbourne to highlight the need for greater government focus on the value of consumer centred primary care within the National Health Plan. The CHF proposal to establish a bi-annual Consumer and Community Roundtable to continue this work was wholeheartedly supported by the Minister who also thanked CHF for developing an issues paper which he said would be carefully reviewed. In brief the issues paper sets out consumer priorities for a National Health Plan featuring two essential starting points:

- reforms to strengthen Australia’s primary health care system to make it more consumer centred, prevention-oriented, better integrated with hospital and social care and added capacity to support transitions of care; and
- boosts to investment in health systems research, shaped by consumer and community priorities, to stimulate services that reflect advances in health sciences and knowledge.

The issues paper and summary can be found at the following links:


Many thanks to Cancer Voices supporters (Julie Marker, Elisabeth Kochman, Debra Kay, Diana Voss) who provided me with feedback on the issues paper and enabled me to bring well considered input to the roundtable. I would also like to thank Cancer Voices New South Wales for funding my flight to the meeting and Cancer Voices SA who paid for my accommodation. We were able to cover this thanks to all those who supported our Movie Fundraiser in July! Thank you for your support. Cancer Voices SA is an independent consumer advocacy group representing South Australians affected by cancer.

Chris Christensen Chair, CVSA

Note: We will provide further information regarding the status of funding issues for Radiation equipment in our next newsletter.