



Message to Members

We now find ourselves in the last few weeks of the year and the pace is certainly not slowing. Recent months have seen intense activity in all areas of our work including a strong focus on both our state and federal governments with both heading to the polls in 2019. NSW is well and truly in election mode as the 23 March polling day draws closer.

At a state level we have embarked on our election strategy of targeting and meeting with key MPs and party representatives. Further details are on Page 4.

At a national level we have participated in an election forum program convened by Consumers Health Forum Australia to develop a national policy platform. We have also provided feedback on the **draft standard for informed financial consent** to give greater transparency to patients when trying to understand treatment costs. This was presented at the recent Clinical Oncology Society of Australia Annual Scientific Meeting in Perth and is now out for wider comment. See Page 10 for the links and opportunity to provide comment and have your say.

Cancer Voices wishes to acknowledge and congratulate the national health consumer organisation, Consumers Health Forum Australia, on three decades of shaping health in Australia. This milestone was celebrated at an event in Canberra.

The CVN Executive has continued to analyse our **Members Survey** which has informed us on what we do well and where we can improve. This has been a valuable exercise and will form the basis and focus of our activity in 2019 and beyond. A detailed report can be found on Page 2.

Training for consumer involvement in research, both our Consumer in Research (CIR) program and for consumer evaluation panel involvement, and consumer advocacy occurred in September and October. The CIR training has seen around 20 new

research consumers join our program. The advocacy training has also attracted some new members to Cancer Voices NSW.

An exciting development is the **Sally Crossing AM Award for an Outstanding Outcome in Cancer Research**, which will recognise “*outstanding achievements in cancer research, consumer involvement and delivery of significant benefit to the cancer community*”. Further details are on Page 7.

Once again, the achievements and innovation of researchers have been showcased at the annual **NSW Premiers Research Awards**. The commitment, dedication, passion and enthusiasm were all on display as recipients accepted their awards.

Our **2019 AGM** will be in **February**. Details regarding **date, time and venue** can be found on the **Noticeboard on Page 2**. Members are welcome to attend. If you would like to become more involved, please contact us and / or come along and meet us. The AGM will be followed by a Members’ Forum where you can contribute to our forward planning. Our 2018 annual report will be presented at the AGM and then published in our March newsletter.

This is our final newsletter in this format. 2019 will see us embracing an electronic format. We will still send a printed version to those who request one. Please email us if you prefer to continue to receive a print version. See Page 4 for details.

As 2018 draws to a close, we extend our thanks to all for your ongoing support and feedback throughout the year. Our very best wishes to our supporters, stakeholders, members, and our active consumer representative base.

A safe and enjoyable Christmas and holiday period to you all.

**Elisabeth Kochman (Chair)
and the Cancer Voices Executive Team**





CVN Notice Board



NOTICE OF ANNUAL GENERAL MEETING 2019

Cancer Voices NSW Inc. invites you to attend its AGM on 15 February 2019 at 11.30am, Level 1, 280 Pitt Street Sydney.

Nominations for the Executive Committee and Office Bearers are invited.

Nominees should be supported by their voting member cancer support or advocacy group on the **Nomination Form** provided with this Newsletter

Please complete and mail to PO Box 713, Milsons Point NSW 1565 or scan and email to info@cancervoices.org.au by 8 February 2019.

If you are interested in working with CVN's Executive Committee, we encourage you to contact us.

If you plan to attend the AGM, please advise us by 8 February 2019.

After the AGM, stay to participate in our Members' Forum!

Consumer Advocacy Training – 2019

Connect with like-minded people and develop your advocacy skills

Friday 1st and Saturday 2nd March, 2019

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*

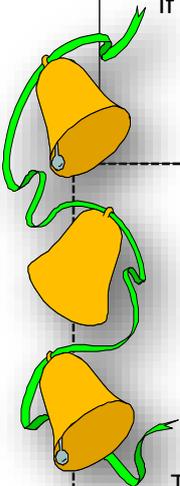
Apply online: http://www.canact.com.au/advocacy_training

Phone Carolyn: (02) 9334 1855

Email: advocacy@nswcc.org.au

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

Read more at <https://www.cancercouncil.com.au/23466/get-involved/volunteer/take-action-for-cancer-issues/consumer-advocacy-training/#KltPEgrFE83vz451.99>



❖ SAVE THESE DATES

COSA SURVIVORSHIP CONFERENCE 2019

28-29 March 2019

Rydges World Square Sydney NSW

Theme: Future of cancer survivorship:
evolution or revolution?

Further details: survivorship2019.org

PATIENT SYMPOSIUM 2019

29-30 April 2019 at the International Convention Centre (ICC) Sydney

"This Symposium (PExS2019) aims to bring people together, providing the opportunity for people to network, learn and share their ideas, work and projects with each other, building our knowledge of patient care.

PExS2019 provides a forum for people to present innovative work and initiatives aimed at improving care across NSW and Australia".

<https://www.e-award.com.au/2019/patientexperience/newentry/about.php>



CVN Committee News

The CVN Executive Committee met face to face on 26 September with our survey a major focus and by teleconference on 28 November where, given that it was our last meeting for 2018, we addressed a very extensive agenda.

The success of any organisation is not down to any one person. Teamwork is critical and we have seen that at work this year. We have found that with good planning and a collaborative approach, some of us were able to step away from our responsibilities at various times and everything continued to run smoothly.

Year-end thanks....We cannot end the year without acknowledging our behind the scenes support: Kathryn Leaney (newsletter and workshop facilitation), Sharon Pannewitz (database, labels), Sandra O'Sullivan (matters financial) and Geoff Vass from Cadrow TECH who continues to support us with all IT matters.

Cancer Council NSW has given us wonderful support since we began in 2000 with the printing and posting of our newsletters, and we cannot forget the packing team. Mindful of costs, resources, efficiencies and our survey response, we have taken the decision to go to an electronic newsletter format beginning in 2019.

For the second year, special thanks also to Health Consumers NSW who have provided us with a base for our Executive Committee meetings.

Our sincere thanks and best wishes to you all.

Member Survey results

The membership of Cancer Voices NSW is its greatest strength. The commitment of so many people to the improvement of the lives of people with cancer forms the basis of everything that we do. This can be through our Consumers in Research program, our advocacy across a range of diagnosis, treatment and care issues, or simply the friendships that can form with like-minded people,

Earlier this year, the Executive Committee decided that we need to both update our membership records and to hear from you about how we might improve our operations, and that the best way to do this was through a survey that could be completed either online or in hardcopy form.

The response rate of around ten percent of the membership (just over 50 people) is considered to be close to the standard proportion of people who respond to surveys of this kind. Some of the statistical information provided by the survey indicates that:

- the majority of respondents have been members for 2-5 years, with 60% identifying as female, and 60% aged between 50 and 69
- people find out about Cancer Voices through a friend, at a meeting or conference, or through another cancer-related organisation
- the three most important reasons people have for joining CVN are to:
 - define issues that are important to cancer consumers and to advocate for measures to address them
 - work towards ensuring access to the highest quality treatment and support services
 - influence the direction of research into causes, prevention, optimal treatments and support.

The results indicate that the three things that respondents believe CVN does well are:

1. provision of the Consumers in Research program;
2. contributions to cancer-related decision-making bodies such as boards, committees and working parties;
3. involvement in Cancer Council NSW's Consumer Advocacy training.

In analysing the consolidated responses, the Executive Committee has identified the opportunity to focus on the following elements of CVN's operation for implementation now and over the course of 2019:

- **Consumers in Research (CIR) program:**

Given that survey respondents ranked the CIR program as the thing that CVN does best, and as it is for many people the 'public face' of CVN, there is a need to ensure that it continues to meet the needs of researchers, research institutions, and research consumers into the future. The opportunity exists therefore for the program to be developed so that it is still seen as a valuable resource in the shift to 'patient led' research. As importantly, particularly as we head into our 20th year in 2020, CIR needs to

anticipate, and be at the forefront of, the evolution of cancer research.

- **Member engagement and relationship management:**

CVN can only continue to grow if it is able to answer some basic questions:

- Why should I join?
- What do I get out of it?
- How can I contribute?

In that regard, a challenge for 2019 will be to reinvigorate our membership, ensure that recently-joined members feel that they want to contribute, and to widen the areas of involvement beyond those that have previously been available. We can achieve this by taking a 'relationship management' approach whereby members are actively engaged, and feel valued for the work that they do.

There is an opportunity for CVN to develop a more active and current presence in the online environment, through a redesign of the website and the development of a social media presence, particularly through FaceBook, Twitter and LinkedIn. This will allow us to utilise the benefits of immediacy in the provision of information to members and to build a broader reach into the wider cancer community

- **Cancer Voices NSW newsletter content and format:**

Respondents indicated that they would like to see a shift in the focus of the CVN newsletter content so that it provides more information about cancer research, *'particularly that where CVN people have been involved as consumer representatives so that*

members can see the impact our CIR program is having', and 'more information about new consumer advocate-attached programs or research and more about their program and outcomes' with less about what members of the Executive Committee are doing.

An opportunity for members to help further shape CVN's direction will take place following the 2019 annual general meeting, when a members' forum will be held for you to provide your ideas as to how we can continue to build our voice. Refer Noticeboard on Page 2.

The Executive Committee thanks Kathryn Leaney for her input in preparing the survey for electronic transmission and response and in shaping the questions in it, and Geoff Vass for his work on technical aspects of its distribution.

Murray McLachlan

PLEASE NOTE:

This issue of the newsletter will be the last that is produced as a print document. The first newsletter of 2019 will be prepared and distributed as an electronic-only publication. A printed version will continue to be sent to those who would like to continue to receive it in print form.

If you want to continue to receive a printed version of the newsletter, please email: info@cancervoices.org.au

CVN Advocacy Update

2019 State Election Strategy

As part of our election strategy and relationship building with state political parties, MPs and representatives, Cancer Voices NSW has had several meetings through October and November including:

- Liberal Party; NSW Health, Director of Policy, 4 Oct
- (Former) Opposition Leader, Luke Foley MP and Shadow Minister for Health, Walt Secord, MLC, 4 October

- Shadow Minister for Medical Research, Tania Mihailuk MP, 17 October
- National Party: Parliamentary Secretary for Regional and Rural Health, Leslie Williams MP, 15 November.

The key issue that we took to these meetings was that of fair and equitable access with subsidies under the Isolated Patient Transport Accommodation and Assistance Scheme (IPTAAS), including clinical trials.

There were some changes to IPTAAS effective 1 October. We believe that there could be some further announcements soon.

At these meetings we also had some additional time to raise other issues including care coordinators, lymphoedema and the status of the Palliative Care report based on the state-wide consultation through 2017. Care coordinators will be an ongoing discussion and lymphoedema is certainly on the agenda (refer following article). We also believe that the government is on track to release the new framework for palliative care before the end of the year.

We will continue this program of engagement in 2019 in the leadup to, and following, the NSW State election which is scheduled to take place on Saturday, 23 March. **Elisabeth Kochman & Murray McLachlan**

Lymphoedema action for NSW continues

Representatives of the Lymphoedema Action Alliance (LAA) met with NSW Health Minister Hon Brad Hazzard MP and staff on 9 October.

Discussion covered many issues of dealing with lymphoedema including types; lack of public treatment services, particularly rural; patients being unable to attend hospitals out of their local health district; complications and consequences of cellulitis – the Government has confirmed that cellulitis was now the number one highest presentation to Emergency Departments; financial, physical, social and psychological aspects; difficulties with data collection; therapists are trained, however there are no jobs for them (many eventually find work elsewhere); issues with coding and the Independent Hospital Pricing Association (IHPA).

An update on *Saving Life 2019* was also provided (lymphoedema is one of four issues forming Cancer Council NSW's Saving Life 2019 campaign priorities).

Planning for further action is underway to tie in with International Lymphoedema Awareness Day on 6 March 2019.



Consumer Advocacy Training 5-6 October 2018

Over twenty participants attended the Cancer Council NSW advocacy training course on 5 and 6 October. The course again provided the opportunity for Cancer Voices NSW to contribute through talking about the opportunities for involvement in our activities.

Lung cancer patient day, 3 September 2018

A Lung Cancer Patient Day was held in Sydney on Monday 3 September. Organised by the International Centre for Community-Driven Research (ICCDR) in collaboration with Lung Foundation Australia, it was designed to help patients:

- navigate the Australian health system,
- understand who is in their multidisciplinary team, and
- provide practical tips and advice to support their everyday living.

Co-hosted by CVN member and patient advocate Lillian Leigh and Dr Catherine Holliday (ICCDR chief executive and long term "friend" of CVN), the event was designed in collaboration with lung cancer patients to address their needs. A feature of the discussion addressed the stigma that some people with lung cancer feel given the assumption that is often made that the person 'must have been a smoker', and the identification of some ways by which to address the stigma.

Key stakeholder organisations, including CVN, were able to take the opportunity to participate in a facilitated discussion to listen to the experience of patients, their needs and expectations of the future, and to talk about how the work of their organisations may address some of those needs. A number of attendees who are also CVN members contributed to this valuable discussion.

Congratulations also to Lillian Leigh who has recently been appointed to the Cancer Australia Advisory Council as a consumer advocate. Lillian was appointed at the same time as the former NSW health minister, Jillian Skinner.

Murray McLachlan

The next advocacy training workshop will be held on **Friday 1st and Saturday 2nd March, 2019**. You can [Click here](#) to register your interest to attend or to be kept informed about future training opportunities. For more information about the training, you can email: advocacy@nswcc.org.au

Murray McLachlan

The Voices being heard

Meetings:

- COSA Teletrials Consortium (teleconference), 12 September
- Consumer in Research Training (CCNSW), 20 Sept (details P6)
- Consumer Review Panel Training (CCNSW), 21 September
- CVN EC Meeting, 26 September
- CA Intercollegiate Advisory Group, 27 September
- Integrated Shared Care Model for Early Breast Cancer Implementation Project teleconference: 2 October
- Consumer Advocacy Training (CCNSW), 5-6 October
- RANZCR FRO Council, 19 October
- CCA Rare & Less Common Cancers Resource project (teleconference) 22 October
- TGA re launch of new access strategies for medications, 1 November
- Consumers Health Forum Aust W/shop, 5 November
- RANZCR Interventional Radiology Committee teleconference: 7 November
- Lymphoedema Action Alliance (LAA) meeting, 13 November
- CVN EC Meeting, 28 November
- Cancer Institute NSW, 3 December
- CCNSW, 7 Dec, 11 December
- UTS, October-December, various / ongoing

Pre-Election Program – MP / Party Representative Meetings

- NSW Health, Director of Policy, 4 October
- Opposition Leader, Luke Foley and Shadow Health Minister for Health, Walt Secord, 4 October

- Tania Mihailuk MP, Member for Bankstown, Shadow Minister for Medical Research, 17 October
- Leslie Williams MP, member for Port Macquarie, Parliamentary Secretary for Regional & Rural Health, 15 November

Conferences / Forums / Events

- Sydney Cancer Conference, 11-12 October
- Launch Cost Analysis of Cancer Treatment & BCNA Pink Ladies Event, Old Parliament House, Canberra, 17 October
- Dept Health Roundtable, Canberra, 29 October
- RANZCR Annual Scientific Meeting, Canberra, 25-28 October
- Premiers Research Awards Presentation, 2 Nov (details P8)
- Cancer Council NSW's Saving Life 2019 campaign launch, Terrigal, 7 November (details P9)
- Health Consumers NSW Annual General Meeting: 9 November
- HCNSW AGM, 9 November
- Cure Cancer Research Event, 22 November
- Consumers Health Forum Australia AGM & Three Decade Celebration, Parliament House Canberra, 26 Nov (details P12)

Submissions/ Feedback / Recommendations

- Medicare Benefits Schedule Review Taskforce (details P11)
- Cancer Council Australia Informed Financial Consent Standard (see P10)



Consumer Involvement in Research (CIR)

A new group of recruits undertook the CIR training program in September at the Cancer Council NSW. These twenty enthusiastic members have been added to our data base, which now sits at approximately 100. They bring a wealth of experience and expertise and will provide great insight as they contribute their perspective to research projects and cancer committees.

The September training followed last year's format, with trainees undertaking the theory section of the training course online. The link to the online section of consumer training is available on the Cancer Council Australia website. It is a series of four short modules, designed to inform and prepare consumers to be involved in health and medical research. Once the trainee completes the modules, Cancer Council NSW runs a face-to-face half day workshop at its Woolloomooloo office.

In the workshop the consumers meet researchers, workshop scenarios and are involved in discussions which prepare them for their contribution to cancer research.

I would like to thank the Cancer Council NSW, in particular Jane Hobson and Karlie Neilson, for their hard work and dedication to ensuring the ongoing success of the CIR program.

Researchers are commencing to send requests for consumers as they prepare their projects for the 2019 funding cycle. December to March is a busy period for our CIR program as requests via our website flow in. Please check your emails daily and respond to any emails from Cancer Voices as soon as possible, so that matching can be undertaken within a short time frame. There have so far been 7 requests for consumers to be involved with research projects in the 2019 funding cycle, with 13 consumers undertaking this important role.

Lee Hunt

NSW Premier's Research Award



The 2018 Premier's Awards for Outstanding Cancer Research were held in Sydney on 2 November.

The annual NSW Premiers Research Awards night was held on 2 November, and hosted by Professor David Currow, Chief Cancer Officer and CEO of the Cancer Institute NSW. This event “celebrates excellence and innovation in cancer research”. The Hon Brad Hazzard MP addressed the gathering on behalf of NSW Premier Gladys Berejiklian. Minister Hazzard acknowledged and thanked the researchers for their dedication and delivery of outstanding outcomes in cancer research.

The 2018 *Outstanding Researcher of The Year* was awarded to Professor Georgina Long from the Melanoma Institute Australia. Huge advancements have been made in focusing on targeted therapies and immuno-oncology in Melanoma. “It was Australia’s cancer,” Professor Long said on receiving her award.

Six other award categories were announced for exceptional research. Full details can be found at

<https://www.cancer.nsw.gov.au/about-us/events/premiers-research-awards>

Shirley Baxter

New Research Award in honour of the late Sally Crossing AM

Cancer Voices NSW is delighted to announce a new research award, **The Sally Crossing AM Award for an Outstanding Outcome in Cancer Research**.

This award has been a collaboration between Cancer Council NSW, Cancer Voices NSW, the Belalberi Foundation and the Crossing Family. It will “recognise outstanding achievements in cancer research, inclusion of consumers and delivery of significant benefit to the cancer community”

This is a generous \$50,000 individual award dedicated to the memory of the late Sally Crossing AM and provided by the Belalberi Foundation and the Crossing Family.

Deadline for applicants is the 14th December, 2018.

Full details can be found on the Cancer Council NSW website at

<https://www.cancercouncil.com.au/research/for-researchers/sally-crossing-award/>

Shirley Baxter



Shaping the Future - Indigenous people and cancer

The Centre of Research Excellence in Discovering Indigenous Strategies to improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT) was established in 2013 and funded by the National Health and Medical Research Council. Additional funding was obtained later that year from a Strategic Research Partnership to improve Cancer control for Indigenous Australians (STREP CA-CInDA), which was funded through Cancer Council NSW with supplementary funding from Cancer Council WA. At that stage, relatively little was known about the needs of Indigenous cancer patients and their families. DISCOVER-TT and STREP aimed to address these knowledge gaps and bring together key researchers,

health professionals and consumer advocacy groups from across Australia. Many achievements have been made under this research program since 2013.

DISCOVER-TT and STREP activities have included:

The National Indigenous Cancer Network (NICaN) was established to improve outcomes for Indigenous people with cancer, including their carers, families and communities. NICaN brings together Indigenous audiences, cancer survivors, service providers, researchers and health professionals from a broad range of disciplines, as well as private sector, government, and non-government organisations. Through NICaN, Ambassadors, who are cancer survivors and carers share their stories and help others understand cancer and the importance of screening.

The program has resulted in thirty-five research papers, with many more still to be published. These publications reflect the broad range of areas covered in the research program, including: screening, co morbidities, supportive care, palliative care, traditional and complementary medicines, out-of-pocket costs, service innovation, epidemiology, and research priorities.

The World Indigenous Cancer Conference in 2016 was the first conference focusing on cancer among Indigenous populations globally. The presentations reflected the broad range of delegates' experiences and backgrounds. An important part of the program was the Yarning Circle dedicated to First Nations people sharing their stories.

The National Indigenous Bowel Screening Pilot aimed at making bowel screening more accessible for Indigenous Australians and to improve screening rates. Consultations in 2015-16 found many barriers to participation could be addressed if eligible Indigenous people received the screening kit directly from a trusted health professional at their local health care service. To address these barriers the Pilot involves around 50 primary health care centres handing bowel screening kits directly to patients.

One research project found that Indigenous women participate less in cervical screening compared to non-Indigenous women. Positive findings showed that for the third of Indigenous women that did participate in screening, most had a previous history of screening. To work towards closing the participation gap, there is now a project being conducted on Screening Matters to better understand the views of women who both 'do and don't' screen.

A culturally appropriate tool was developed to assess supportive care needs of indigenous cancer patients.

This tool was found to be acceptable to patients and clinical staff and training significantly increased the confidence and knowledge of staff. This tool is currently being implemented into routine care around Australia. Another tool is now being developed to assess the unmet needs of caregivers of indigenous cancer patients.

Researchers have developed an online curriculum training package for health science students and health care professionals that explores themes of culturally safe practice, clinical yarning and communication, community education about prevention and overcoming delays in diagnoses, support systems and the importance of family. Narratives are incorporated into the training, empowering Indigenous people to

actively seek medical advice, to question, to ask for second opinions and to listen to their own bodies. Feedback from medical students revealed their heightened awareness of early detection and diagnosis and effective communication skills particularly around end-of-life wishes.

Future direction and activities were recently work shopped

at a roundtable held in September, which focused on 'Envisaging and building a future that best supports Aboriginal and Torres Strait Islander peoples affected by cancer'. The new program of work will aim to:

- increase cancer prevention and early detection through immunisation and screening;
- improve diagnosis and treatment through health service innovation; and
- provide appropriate care to enhance psychosocial wellbeing of Indigenous cancer survivors, their partners and carers across the cancer continuum.

Note: CVN's involvement in indigenous cancer work began with the late Kathy Smith in 2014.

Lee Hunt



Consumer Members of DICSCOVER-TT – (L-R) Adelaide Saylor, Lee Hunt, Aunty Marg Lawson



Consumers Included – Seal of Approval – Now trademarked!

For more information contact: info@consumersincluded.org.au

and the Ci tab on Cancer Voices Australia's website www.cancervoicesaustralia.org.au



From Cancer Australia – Just Released!

New resources to support best practice care for people affected by lung cancer

The ***Lung Cancer Framework: Principles for Best Practice Lung Cancer Care in Australia*** is a national resource for health professionals, service providers and policy makers who are involved in the care and treatment of people affected by lung cancer across Australia.

Cancer Australia has released two resources to support the adoption of the Lung Cancer Framework: a resource for consumers and a resource for health professionals.

Both resources aim to improve the outcomes and experiences of people affected by lung cancer in Australia, irrespective of where they live.

The [Consumer Guide](#) contains guidance on what people with lung cancer can do to participate actively in conversations with their health professionals, and make informed, evidence-based decisions about the cancer care that is right for them.

The [Guide for Health Professionals](#) contains evidence-based information and best practice strategies, tools and resources to support adoption of the Principles into best practice lung cancer care.

These two new resources released by Cancer Australia, used in conjunction with the [Lung Cancer Framework](#), will support health services to provide best practice care and ultimately improve outcomes and experiences for people affected by lung cancer across Australia.

The development of the Lung Cancer Framework and resources was guided by systematic reviews of the evidence and a national demonstration project undertaken with four health service collaborations. The development process was informed by consultations with health professionals and consumers and guided by Cancer Australia’s Lung Cancer Advisory Group.

Share the resources amongst your networks to ensure the best possible care for all people affected by lung cancer. To access the resources, visit www.canceraustralia.gov.au

CCNSW Saving Life 2019 campaign launch, 7 November

The first event in Cancer Council NSW’s Saving Life 2019 campaign launch program was held in Terrigal on the NSW Central Coast on Wednesday, 7 November. The breakfast event was well attended, with the Liberal member for Terrigal, Adam Crouch, ALP member for Gosford, Liesl Tesch, and ALP candidate for Terrigal (also representing David Harris, member for Wyong) Jeff Sundstrom, each speaking and expressing their support for and commitment to taking the CCNSW election priorities to their parties for endorsement. The campaign calls on the next NSW government to commit to reducing the impact of cancer by:

- protecting workers and patrons from second-hand smoke in pubs and clubs
- banning tobacco vending machines and introducing a tobacco retail licence fee
- removing junk food marketing from government owned property, and
- funding public lymphoedema services across NSW.

The issues were brought to life by three speakers from the Central Coast who shared their personal experiences:

- Mark Davison gave a message about the health impacts he suffered working in the smoking ‘room’ (an area open to the outside in theory) at a local club. Fortunately, he spoke up and doesn’t have to service the smoking area any more, but his colleagues still do
- Clara Peto, a medical scientist at a Central Coast hospital, spoke about the growing number of overweight children and young people she sees in her work, and her support for Cancer Council’s proposal to reduce junk food advertising
- Alison Mortiss spoke movingly about her experience of having lymphoedema and the difficulties of accessing treatment through the public health system. Prior to the event, Alison had been interviewed on ABC local radio.

Murray McLachlan



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

As this will be the last printed version to be packed and posted in bulk, we want to extend a very big thank you to the packing team, without whom we would never have been able to do what we have done.

A Different Consumer Engagement Model

In addition to formatting the CVN Newsletter, I am also a member of the Consumer Advisory Panel (CAP) for the Translational Cancer Research Network (TCRN) based at the University of NSW. This TCRN is one of 7 Translational Cancer Research Centres funded by Cancer Institute NSW and currently has a number of universities, hospitals and research facilities as members.

The CAP currently has 13 members, all trained in consumer engagement and willing to learn and actively participate. All of us have been impacted by cancer in some way and we are dedicated to working with researchers to improve the experience for others.

The CAP was established in 2012 with the aim of developing a strategic model of consumer engagement in research that provides multiple platforms for researchers to engage consumers in their research.

We do this in three main ways:

- We hold annual information workshops for researchers to inform them about the fundamentals of consumer engagement in research and present successful consumer-researcher case studies;
- We also hold CAP group sessions, in November and the following February, designed to provide a platform for researchers to present their research and gain valuable feedback from the CAP members, prior to submitting their grant applications;

- And there is the 1:1 researcher-consumer partnerships for in-depth and ongoing consumer involvement.

In addition, TCRN consumers participate actively in the TCRN flagship projects as stakeholders and regularly share their engagement in the flagship projects with other consumers.

This approach to consumer engagement is very successful, due in part to the enthusiasm of the CAP members and also to the fabulous TCRN Project Officer, Stella Jun and Program Manager, Stephanie Macmillan. In the recent TCRN membership survey, consumer engagement was selected as one of the most valued research support services provided to its members.

Since its establishment in 2012, the CAP has:

- Partnered and provided consumer input to over 75 research projects including the TCRN flagship projects;
- Spoken with more than 150 researchers who have attended Information sessions;
- Engaged with 40 TCRN-supported PhD students, connecting them to real-world outcomes and helping them effectively communicate their research from the earliest stages of their careers
- Partnered with three TCRN members who were awarded major research grants in 2017;
- And significantly raised the profile of consumers in research.

More information is available at: www.tcrn.unsw.edu.au

Kathryn Leaney



Have your say! Informed Financial Consent – public consultation feedback

Cancer Council Australia, Breast Cancer Network Australia, CanTeen and Prostate Cancer Foundation of Australia propose a standard for informed financial consent as a key component of delivering quality care. The standard supports doctors and practices to engage in activities that enable greater transparency around fees charged to enable patients to better consider the likely financial impact to them.

To access <https://www.cancer.org.au/about-cancer/patient-support/informed-financial-consent.html>

Public feedback period

We invite people to review the proposed standard and provide feedback by **COB 15th February, 2019**.

Please provide feedback via the form at:

<https://secure.fundraising.cancer.org.au/financial-consent-survey/index.html>

Feedback received will be considered in finalising the standard.

Feedback will remain confidential. If you would like to be notified when the standard has been finalised, you can leave your name and email address at the end of the form.

Source: Cancer Council Australia website

Note: Cancer Voices provided comment on the initial draft and is very supportive of this initiative

It has been another busy period for Cancer Voices Australia (CVA) to ensure that the consumer perspective is represented in the updating of cancer guidelines and policies. As cancer research has led to the development of new treatments and technologies, there is a constant need for review by stakeholders.

Medicare Benefits Schedule (MBS) Review Taskforce

The MBS taskforce is undertaking a program of work to consider how more than 5700 items on the MBS can be aligned with contemporary clinical evidence and practice in order to improve health outcomes for patients. The taskforce has established Clinical Committees and Working Groups to undertake clinical reviews of MBS items. The existing MBS Schedule, which is 30 years old, is outdated. It does not allow for responsive changes to advances in medical oncology treatments and developments in technology for radiation therapy.

Cancer Voices provided feedback on the recommendations put forward by the Urology Clinical Committee and the Diagnostic Imaging Clinical Committee - Breast Imaging. Issues that were raised in our responses included:

Out-of-pocket Costs for Imaging Procedures

Diagnostic imaging is an essential component of looking after a woman's health; it is a necessity rather than a choice. Breast cancer is still the most common cancer affecting Australian women. Some women are able to access services where there are no out-of-pocket costs, whereas many are not able to access bulk billing. For those who have had a diagnosis of breast cancer the cost can add up to thousands of dollars if multiple follow-up tests, or more expensive tests such as MRI or CT scanning, are required. Imaging tests add to the significant financial burden of a breast cancer diagnosis. It is of great concern to Cancer Voices that women may choose not to undergo regular follow up mammograms and ultrasounds due to the prohibitive costs.

It is essential that the MBS rebates for imaging services are increased to better reflect the cost of providing services and to reduce the out-of-pocket costs faced by patients. The rebates have not been indexed for over

20 years and do not reflect the rise in the cost of living and the increasing costs of providing imaging services.

To ensure that all patients with a breast cancer diagnosis receive high quality, clinically appropriate and cost effective care CVA asked that the MBS Review Taskforce address the high out-of-pocket costs of diagnostic imaging. It is vital that there is an increase in the Medicare patient rebates. We urged the Taskforce to make recommendations to the federal Minister for Health, for consideration by Government, to increase the imaging rebates for patients.

The Multiple Services Rules for Breast Imaging

Patients experience inconvenience and additional costs as well as unrealistic and disproportionate rebate reductions due to the rules regarding the provision of multiple diagnostic imaging services on the same day.

A patient presenting with a breast lump typically undergoes routine diagnostic mammography and ultrasound examination. The mammogram and ultrasound images are reviewed by a breast clinical radiologist and there is communication with the referring medical practitioner regarding the results and a discussion regarding the need for a biopsy.

If a breast biopsy is to be performed, Medicare will not pay for an ultrasound-guided biopsy unless there is a 3 hour time separation between breast ultrasound and the biopsy. The patient has to either wait three hours prior to undergoing an ultrasound-guided biopsy or agree to pay a large out-of-pocket fee to have the examination conducted quickly and efficiently. Patients are frequently scheduled to return the next day so that they are not penalised by the Multiple Services Rules. Patients can pay large out of pocket expenses to have an efficient service with all imaging, including a CT-guided biopsy, performed on the same day.

Cancer Voices urged the Taskforce to recommend that changes be made to the current rules to address the issues of patient inconvenience and additional costs resulting from the Multiple Services Rules.

Multidisciplinary Clinics for Prostate Cancer Care

Cancer Voices Australia supports the use of multidisciplinary clinics for the wide range of cancer types, as they are the cornerstone of modern cancer care and

represent best clinical practice. They allow specialists from different disciplines to contribute to and coordinate an optimal and effective treatment management plan. A single-discipline specialist is unlikely to be able to advise on the different treatment options available to help ensure a person who has been diagnosed with prostate cancer is aware of the range of treatment options. If a multi-disciplinary clinic is not feasible, improved patient outcomes are more likely if the person is referred to both a urologist and a radiation oncologist.

Lee Hunt

Consumers Health Forum Australia (CHFA) turns 30!

Cancer Voices acknowledges and congratulates CHFA on thirty years of shaping health in Australia.

CHFA celebrated **Three Decades of Consumers Shaping Health** on 26 November at an event at Parliament House, Canberra. Guests were welcomed by Tony Lawson (Chair), who later launched a White Paper: ***Shifting Gears – Consumers Transforming Health***. Speakers included Leanne Wells (CEO) who spoke and facilitated a panel discussion on the early years. Another panel discussion focused on the future. There were addresses by Hon. Greg Hunt MP, Minister for Health, Hon. Catherine King, Shadow Minister for Health and Senator Richard Di Natale, Leader of the Australian Greens. Former Labor MP Neal Blewitt, who

was the minister for health in 1988 and responsible for the funding approval for the establishment of CHFA, gave the closing address.

White paper Shifting Gears – Consumers Transforming Health can be found at:

[https://chf.org.au/sites/default/files/181125_shifting_gears - consumers transforming health.pdf](https://chf.org.au/sites/default/files/181125_shifting_gears_-_consumers_transforming_health.pdf)

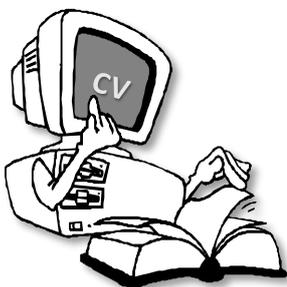
(Note: CVN is a voting member of CHFA)

Consumers Health Forum Australia (CHFA) national election priorities

With a federal election on the agenda for 2019, CHF Aust commenced a series of members' forums around Australia in November to "hear and discuss national health priorities in preparation for the Policy Platform CHF will promote during the campaign". Forums were held in Sydney, Adelaide, Melbourne and Canberra. Cancer Voices participated in the small but very focused and engaging Sydney forum on 5 November. It's no surprise that one of the top concerns is that of affordability and accessibility of health care. Input from all workshops has been pulled together and presented through a webinar on Wednesday 5 December. There will be further opportunity to provide comments on this national platform.

Elisabeth Kochman

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



NEED FOR ACTION! NEED FOR ACTION! NEED FOR ACTION!

This will be the **last issue** of the CVN Newsletter to be produced in hard copy.

The first issue of 2019 will be produced and distributed electronic form.

In order for us to stay in touch, we really need your current email address.

Please send to info@cancervoices.org.au

If you want to continue to receive a printed version of the newsletter, please let us know by email to info@cancervoices.org.au

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.
