

**W**elcome to the Summer/Autumn Newsletter.

Sometimes it is useful for us to revisit our history. Many people are not aware of where consumer advocacy in cancer first began. It is also interesting to reflect on the groups to which we belong. We encourage you to share your views and ideas on where we are now and what we could be doing more of.

### Looking back—into history

#### Where did cancer consumer advocacy begin?

##### **Breast Cancer Action Group -The first!!**

From: Breast Cancer Action Newsletter No. 1 June 1994.

*On Good Friday, The Age newspaper published a short interview with Marcia O'Keefe. Marcia, who was diagnosed with breast cancer five years ago, has frequently spoken out to urge better services for women suffering from the disease. She has been active in publicising the need to improve breast cancer treatment and to help women make their own decisions on treatment, together with their doctors. She serves on several working parties and committees, representing the women who have, or may one day have the disease.*

*Marcia said, 'I am tired of the horror stories I hear from women...who are told there is nothing more that can be done for them, of the women who are told they will die within three months, of the women given no choice between mastectomy and conservative surgery where either are suitable, of the way women are stripped of their dignity by medical professionals.'*

*In the interview, Marcia expressed her wish to establish a breast cancer action group which could help improve the treatment of the growing numbers of women who*

**T**he Committee of Cancer Action Victoria has decided that we will reduce the number of newsletters we produce in a year to two – Summer/Autumn and Winter/Spring. We do not have an income stream and we have a limited group of members who contribute to the newsletters.

We also want people to receive the newsletter on-line. With increases in postage costs and the costs in printing we cannot continue to post out the newsletters without asking for a contribution to cover costs. To this end, please send in an email address or if you really do not have an email address please let us know if you do want a printed copy and whether you are willing to pay for postage.

We intend to supplement the newsletters with regular on-line updates using Mailchimp. This will also be used to email requests for consumers to participate in research, clinical trials, committees etc.

*will contract this disease in their lifetime. Such a group would be able to make submissions to inquiries, nominate consumer representatives on working parties and steering committees, and to lobby for better treatment practices, better facilities and more information services for women.*

*As a result of this article, around 35 women gathered a few weeks later in Melbourne.*

The inaugural meeting was held on Saturday May 14th 1994. At the meeting the name of Breast Cancer Action Group was adopted. The first meeting of the Steering Group was held on Saturday 4 June. At this meeting the women decided on the objectives and goals to shape their organisation.

Goals:

- Give women a voice on breast cancer issues;
- Work to eradicate breast cancer, by focussing national attention and by involving women with breast cancer experience and caring others as

- advocates for action, advances and changes; and
- Bring about meaningful progress in breast cancer policy and treatment through lobbying for change and participation in policy setting bodies.

From the original group of women came the women who eventually headed Breast Cancer Network Australia, including the CEO, Lyn Swinburne. BCAG New South Wales followed too.

It is amazing to think that breast cancer advocacy began with one strong woman – Marcia O’Keefe – who took action to harness others in her quest for better treatment for women.

Some other names associated with the beginnings of BCAG include: Sue Lockwood, and Helen Varney.

References:

Breast Cancer Action Group Newsletter, No.1 June 1994

Nicola Bruce. *Makers of meaning: Consumer participation in breast health and the role of women’s contribution in breast health knowledge.* Unpublished PhD thesis, LaTrobe University, November, 2006.

### **Cancer Voices Victoria (CVV)**

Cancer Voices started in the United Kingdom as an initiative of the Macmillan Trust seeking to get patients in the United Kingdom, carers and families to make a difference for others – to be advocates for others in their cancer journey. The first in Australia was Cancer Voices New South Wales. Cancer Voices Victoria was established in 2006.

Cancer Voices Victoria Newsletter, Issue 1 August 2006 set out the following parameters for the group.

#### *About Cancer Voices*

*Cancer Voices Victoria is a state-based advocacy organisation. It aims to provide a unified, independent voice for all Victorians affected by cancer. It is an umbrella for advocacy and support groups. Cancer patients, survivors, carers, medical providers and any interested persons are welcome to be involved.*

*As a network, it provides a forum for people touched by cancer to share issues, ideas and experiences that are common across all cancer types.*

#### *Our Objectives*

- *To provide a forum for Victorians touched by cancer.*
- *To minimise the impact of cancer on the*

*community.*

- *To promote a balanced public awareness of the effects of cancer.*

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Ian Roos was inaugural Chair of Cancer Voices Victoria. Members of the Steering Committee were Les Leckie, Denise Horsey, Maree Gathercole, Vivian Ho, Dorothy King, Neil O’Loughlen, Michael Powell, Claire Vivian, Ethel Wellington, Maurice Wellington and Peter Williams.

Reference: Cancer Voices Victoria, Issue 1, August 2006

### **Moving On**

In 2011 Breast Cancer Action Group Committee agreed to a merger with Cancer Voices Victoria. Michael Powell, Chair CVV, wrote in the Newsletter, Issue 1, Spring 2011 –

*... I am thrilled to welcome those of you who were loyal members of Breast Cancer Action Group Victoria. CVV is greatly enriched and invigorated by the merger with BCAGV. ...The objectives of CVV and BCAGV were similar.*

Breast Cancer Action Group felt its early work was now taken by Breast Cancer Network Australia and that that we should join forces to work for other cancers along with breast cancer.

### **Moving on again**

Cancer Voices Victoria incorporating Breast Cancer Action Group Newsletter, Issue 5, Spring 2012 outlined another change.

*About a year ago, disagreement occurred over the Constitution of Cancer Voices Australia. All attempts to resolve the issues have failed. As a result, CVA was forced to dissolve in June this year. As a consequence of this breakdown legal action has been taken By CVNSW against CVA, CVV (and CVQ, CVWA) over the use of the name Cancer Voices. The Committee of CVV has voted to recommend a name change...Although we would like to continue to use the name ‘Cancer Voices’ the committee considers its further use is unworkable and risks our well earned reputation for collaborative work.*

*The name chosen by the former CVQ, CVWA and a new version of CVA is ‘CanSpeak’. While it is beneficial to have a uniform ‘brand’, there is no obligation for us to use the same name.*

After all the trauma Victoria chose to adopt Cancer

Action Victoria – adopting parts of both the merged groups.

Reference: Formerly Cancer Voices Victoria Newsletter Issue 5 Spring 2012

Following the formation of Cancer Voices Victoria in 2006, other States also formed similar organisations including Queensland, Western Australia, and South Australia. These organisations were independently governed but held similar aims and objectives and were members of the then known Cancer Voices Australia.

The action by Cancer Voices NSW had an extremely negative impact on cancer consumer advocacy in Australia. Funding was lost for a national consumer advocacy organisation and cancer consumer advocacy was put back 20 years. We are now almost starting again in having to gain the confidence of health care providers, policy and decision makers, and others associated with cancer care.

Cancer Voices Australia exists today under a different entity and is not the same as the Cancer Voices Australia that existed prior to the proposed litigation.

Cancer Voices Queensland changed its name to CanSpeak Queensland and continues to operate for people affected by cancer in Queensland. Individual members of CanSpeak also exist nationally and they all enjoy the benefits of friendship and collaboration with Cancer Action Victoria. We are working together to find better ways to provide alternatives to cancer consumer advocacy in Australia from a national perspective and to work more effectively in this arena.

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### A tale of two letters or Why is it so difficult?

*First letter sent to the consultant. Copies to the Medical Director of the hospital, and to the GP.*

**RE: Colonoscopy performed on Mr Aaaaaaa  
30/1/2017, post-operative actions**

Sir,  
On 24/11/2016 your office sent me a reminder for a follow-up colonoscopy. You had previously conducted one in Nov 2013. I arranged a referral from my GP Dr

Xxxxx, and called your office to book the procedure, which was carried out on 30 Jan 2017.

I advised you prior to the procedure, just prior to the anaesthetic being administered, that following the 2013 colonoscopy, I had been diagnosed with prostate cancer, since surgically treated, so was obviously concerned about the possibility of bowel cancer.

In the recovery room, your only comment to me was that the preparation had not been good, that you had removed a polyp, and that I should see my doctor in the next two weeks.

On Feb 3 I receive an invoice from Yyyyyyy for a level 4 biopsy. I rang them to ask if they could also forward the results, they refused to do so. I therefore rang your office, and, after some heated discussion, in which I outlined my concerns, and also pointed out that I am perfectly entitled to see my own medical records, your staff member agreed to send a copy of the results to me by email. She also provided your email address so that I could send a formal request and ensure the email was correct. (Emails attached).

On Monday 6 Feb an email arrived from you with the Colonoscopy Report, which, whilst not what I had asked for, confirmed multiple diverticulae (probably influencing the preparation you had complained about), and one flat 3mm polyp in the rectum that had been resected.

I advised by return email that I still needed the histology report, and that there was little point in my consulting Dr Xxxxx until he also had received a copy. There being no response to this email, I called your office again on Tuesday 7 Feb, to have yet another staffer initially refuse to send me a copy of the biopsy report, despite this being agreed to the previous week. She confirmed that Dr Xxxxx had not been sent a copy either.

After some discussion she advised that she would fax Dr. Xxxxx a copy, and post one to me. It arrived today, with the diagnosis “Rectum- Hyperplastic Polyp”, which, I am advised, is almost certainly benign.

Why was I subjected to 9 days of unnecessary concern about possible bowel cancer, when the biopsy report was available to you on Feb 1<sup>st</sup>?

Why was the report not provided to Dr. Xxxxx until I

prompted your staff to do so?

And do you treat all your patients with the same callous contempt?

*Second letter to the consultant Copies to the Medical Director of the hospital, and to the GP.*

**RE: Colonoscopy performed on Mr Aaaaaaa 30/1/2017, post-operative actions**

Sir,

Thank you for your letter dated 14 Feb 2017, received yesterday, in reply to my letter of 10/2/17. I appreciate and thank you for the apologies contained within it, both for any failure by you to send information to my GP, Dr. Xxxxxx, and for any hurt to my “feelings”.

The rest of your letter, however, is a fairly incoherent defence of your default practice procedure of not providing patients their medical information when requested, on the grounds that to do so may increase anxiety. You fail to address the issue that, as in my case, denial of access to the fact that my biopsy was not cancerous actually *increased* patient anxiety!

You go on to suggest that an exception should have been made in my case on the grounds that I have some medical exposure/knowledge. This is flattering, but completely irrelevant.

Your statements make it clear that you are either unaware of, or choose to ignore, the law on this matter.

The *Health Records Act 2001* (the Act) regulates the collection and handling of health information. The Act gives individuals (patients) a legally enforceable right of access to health information about them that is contained in records held in Victoria by the private sector. (you)

Access to a patient’s medical records can only be denied to the patient (or their nominated representative) in exceptional circumstances, such as:

- a serious threat to the life or health of any individual
- unreasonable impact on the privacy of other individuals
- anticipated legal proceedings where legal professional privilege applies.

Outside of the grounds indicated above, you need to understand that you are NOT the arbiter of which patients can and should receive access to their records.

By instructing your staff to act as they do, you are therefore leading them to act unlawfully. I strongly suggest that you amend your practice procedures and your attitude to patients accordingly.

My leading question remains unanswered:

Why was I subjected to 9 days of unnecessary concern about possible bowel cancer, when the biopsy report was available to you on Feb 1<sup>st</sup>?

*No reply was received*

**Editors note:** Please let us know if you have had a similar experience.

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### Participation rates in Cancer Screening Programs

The participation rates in national cancer screening programs in 2014–2015 ranged across Primary Health Network areas:

For **National Bowel Cancer Screening Program:**

- the national rate was 39%
- the highest rate was 47% in Country SA
- the lowest rate was 29% in Northern Territory.

For **BreastScreen Australia:**

- the national rate was 54%
- the highest rate was 63% in Northern Queensland
- the lowest rate was 36% in Northern Territory.

For **National Cervical Cancer Screening Program:**

- the national rate was 56%
- the highest rate was 64% in Murray (Vic, NSW)
- the lowest rate was 49% in Western Sydney (NSW)

Australian Institute of Health and Wellbeing, May 2017

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### Breacan programs

**What's On:** Free information sessions and activities for



all women diagnosed with breast and gynaecological cancers. The current *What's On* program has lots of interesting sessions to attend, including Tea, Nurturing and Mindfulness on Thursday 22 June, Integrative Medicine: Mind, Body and Spirit on Monday 31 July and

Meditation on Monday 14 August.

Please see the full program online at [www.breacan.org.au/events/](http://www.breacan.org.au/events/) or phone us on 1300 781 500 and we will post a program to you.

**Reflexology:** Reflexology is a gentle therapeutic foot massage provided by a qualified reflexologist. BreaCan offers free 40 minute reflexology appointments once a month on Thursdays.

Booking is essential, so please phone us 1300 781 500.

**Feel Good** is a gentle exercise program, held fortnightly, in the city, and conducted by a qualified fitness instructor. Sessions are open to all ages and all levels of fitness. Phone us to find out how you can register to be involved and when the next session is being held.

Note: BreaCan will launch a new name and logo on the 31<sup>st</sup> May



Would you like to be involved in advancing medical research?

**The Walter and Eliza Hall Institute of Medical Research is excited to offer a new Consumer Representative opportunity.**

The Institute's researchers are seeking enthusiastic members of the public who would like to contribute to better outcomes in the medical research sector.

**About us**

The Walter and Eliza Hall Institute is the oldest medical research institute in Australia. Our affiliation with The Royal Melbourne Hospital links research outcomes with clinical practice to accelerate discoveries for health and disease.

Scientists at the Institute undertake research in a range of areas, preventing and treating diseases including breast, ovarian and blood cancers, type 1 diabetes, rheumatoid arthritis, coeliac disease and malaria.

**What we are seeking:**

We are interested in talking to members of the public who are current or past patients, family members, carers or friends, who are interested in medical research and have a strong desire to help improve research outcomes.

Consumer Representatives do not need to have a science or medical background but to bring to the research the patient's perspective. Our researchers are seeking non-scientific perspectives to assist in communicating scientific information to lay audiences, and relating laboratory research to community experience.

**Helpful requirements:**

- Understanding of consumer issues and links to relevant consumers and consumer groups
- A genuine interest in medical research
- Understanding of consumer issues relating to diseases

Consumer Representatives at the Walter and Eliza Hall Institute are active participants in our Consumer Buddy Program and are well supported and provided with training by our Consumer Coordinator. We aim to ensure that your time with us is enjoyable, exciting and fits in with your life commitments.

To find out more please contact the Consumer Coordinator, Katya Gray at [kgray@wehi.edu.au](mailto:kgray@wehi.edu.au) or phone 0408 525 122

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Combination of ground-breaking treatments offer powerful new path for blood cancer therapies

Media release 28 February 2017

Researchers at Peter MacCallum Cancer Centre and Monash University have identified for the first time how a new class of epigenetic drug engages with the immune system to kill off cancer cells, offering powerful new pathways for enhanced blood cancer therapies.

BET-inhibitors are a relatively new class of drug which work to 'switch off' important cancer-causing genes expressed within tumour cells. International clinical trials of BET-inhibitors for the treatment of blood cancers, such as Acute Myeloid Leukaemia, are now underway including at Peter Mac. However, to date, this research has focused on the direct effects of the drugs in inducing cancer cell death and understanding how resistance emerges.

In research published today in Cell Reports, the team at Peter Mac and Monash have demonstrated the potential for combining ground-breaking epigenetic and immune-based treatments for more potent

results.

Experiments conducted as part of the research, showed that immune-competent mice with lymphoma had a far greater response to BET-inhibitors than their immune-deficient counterparts.

In addition to their primary function, the research showed the BET inhibitors were able to 'switch off' a protein called PD-L1, which is used by tumour cells to hide from the immune system. Through this mechanism, the BET-inhibitors were making tumour cells more sensitive to attack from the immune system.

The power of an activated immune system in eliminating tumour cells has been proven through 'blockbuster' drugs such as 'Keytruda' and 'Opdivo', which also target the PD-L1 pathway. Building on this knowledge, this research confirmed that the combinations of BET-inhibitor with other immune therapies work better in lymphoma than either therapy alone.

Based on laboratory research performed at Peter Mac, the Monash team is currently trialling a combination of a different epigenetic drug called Dinaciclib with the anti-PD1 therapy, Keytruda in relapsed lymphoma, myeloma and chronic lymphocytic leukaemia with further clinical trials for the combination therapy likely to emerge as a result of this research.

This research was supported by the National Health and Medical Research Council of Australia; Victorian Cancer Agency; Snowdome Foundation; Cancer Council Victoria; The Kids Cancer Project, and Roche. Core technologies enabling the research are supported by the Australian Cancer Research Foundation and Peter MacCallum Cancer Foundation.

Peter MacCallum Cancer Centre 1

#### Contacts:

For more information or to arrange an interview with Professor Ricky Johnstone or Associate Professor Jake Shortt please contact the Peter Mac Communications team on 0417 123 048.

#### About Peter Mac

Peter MacCallum Cancer Centre is one of the world's leading cancer research, education and treatment centres globally and is Australia's only public hospital solely dedicated to caring for people affected by cancer. We have over 2,500 staff, including more than

### Have you received neurotoxic chemotherapy?

Researchers at UNSW Australia are seeking volunteers who have received neurotoxic chemotherapy (i.e. chemotherapy that can cause damage to the nerves) as a treatment for cancer to complete an online survey. Through this survey, we hope to better understand the impact of side effects of chemotherapy on the lives of Australian cancer survivors.

Some kinds of neurotoxic chemo include:

Oxaliplatin (Eloxatin, Oxalatin, Oxaliccord, Xalox, FOLFOX, XELOX), Cisplatin (cisplatinum, Platinol), Carboplatin (Carbaccord), Paclitaxel (Taxol, Anzatax, Plaxel, Abraxane), Docetaxel (Taxotere, Dotax, Oncotaxel), Cabazitaxel (Jevtana), Vincristine, Vinblastine, Vinorelbine (Navelbine), Vinflunine (Javlor), Vindesine (Eldisine), Thalidomide (Thalomid), Bortezomib (Velcade), Ixabepilone, Lenalidomide (Revlimid), Pomalidomide (Pomalyst) and Eribulin (Halaven).

If you are uncertain of the name of the chemotherapy you received, you are still welcome to take part in the survey.

The survey is anonymous, and takes around 30 minutes to complete.

If you would like to participate in the study please go to the following website:

<http://www.infocusstudy.org.au/survey/>

Or for more information please

email: [in\\_focus@unsw.edu.au](mailto:in_focus@unsw.edu.au)



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