

February 2013 eBulletin

In this eBulletin we alert you to a variety of activities, articles and publications that may be of interest to you or people affected by cancer. Feel free to forward this on to others.

To print or view as a PDF document: click [here](http://www.cancervoicessa.org.au/information/newsletters-documents.html) for Cancer Voices SA (CVSA) eBulletins (www.cancervoicessa.org.au/information/newsletters-documents.html).

Two simple things you can do to help us:

Support action on Survivorship and 'No to Gene Patenting'!

1. Sign up to the [Flinders Charter of Cancer Survivorship](#).

2. Sign the petition 'No to Gene Patenting', online [here](#) and [download a form](#) to collect signatures. **We ask the Parliament to amend the Patents Act 1990 to clearly exclude the ability to grant patents over human genetic material.** (See more detail of both issues in this eBulletin).

'Raising a voice' - through Advocacy, Involvement, Awareness & Information.

Cancer Voices SA (CVSA) activities



The inaugural Flinders Centre for Innovation in Cancer (FCIC) Survivorship Conference was attended by about 300 clinicians, researchers, survivors and others. There was an encouraging atmosphere of energy, enthusiasm and optimism throughout. Visit the website at: <http://www.fcic.org.au/survivorship2013/default.aspx> for photo highlights on flickr, view many of the slide presentations generously made available by the speakers, and **sign up** to the [Flinders Charter of Cancer Survivorship](#). The ethos of the conference lives on through the Charter by support shown or efforts we now all make to achieve these aims.

Congratulations to Prof Bogda Koczwar, the cheerful, capable, indefatigable conference convenor, Ross McKinnon (FCIC Director) and Maxine Pollard (Flinders Medical Centre Foundation). Cancer Voices contributed from the commencement of Conference planning, throughout the event and now, we are following through with actions. Thank you to all who helped; the work continues. (Photos left: Prof Bogda Koczwar, centre: an enthusiastic group photo, right: CVSA's Ashleigh Moore and Julie Marker signing the Flinders Charter).



Cancer Conversations

Cancer Voices SA led an interactive workshop at the Survivorship Conference, where Ashleigh Moore and Julie Marker presented the Canadian 'GoPublic Cancer Conversations' methodology we have used and adapted for discussing cancer survivorship issues and perspectives. Feedback from our 16 'survivor led' conversations, including 3 in Australian Aboriginal communities, agreed that 'cancer conversations' are an effective way to engage people, the conversations seem an important delivery channel for awareness, education and action, and participants were encouraged to talk to others about their experience. The [abstract](#) and [slides](#) from this presentation are available online.



What matters to a survivor



An insightful and thought provoking talk on '[What matters to a survivor](#)' was given by Dr Agnes Vitry during the first plenary session of the Survivorship Conference.

Coping with the diagnosis of cancer as a new migrant, a mother and the family breadwinner were challenges described by Agnes. (Photo: Dr Agnes Vitry)

Building yourself to better cope

Clare Oakes 'case study of a cycling team led by cancer survivors' was one of the posters presented at the Survivorship Conference. Clare conducted interviews with 7 members of the Cancer Voices SA cycling team as part of her Honours degree in Psychology studies. (Photo: Clare Oakes with Ashleigh Moore)



Meet the Cancer Voices SA (CVSA) 2013 Executive Team

CVSA Executive Team members for 2013 elected at the AGM on 17 December 2012 are: Ashleigh Moore (Chair), Julie Marker (Deputy Chair), Maurice Woolard (Treasurer), Pam Sandys (Secretary), Jim Vlahakis, Dr Agnes Vitry, Con Nakos, Dr Eric Browne and Cholly Winter.

We are all volunteers. If you want to make a difference for those affected by cancer please contact us at info@cancervoicessa.org.au! Tell us your ideas, issues, get involved in our activities and/or consider joining our 'Executive Support' Team. Email is our main form of Exec Support Team communication, so wherever you live, you can be involved.



(Exec Team members at the Survivorship Conference, left to right: Dr Agnes Vitry with Prof Ross McKinnon; Dr Eric Browne and Pam Sandys; Eric, Julie, Prof Bogda Koczwara, Ashleigh & Con Nakos; Ashleigh Moore).

At the National level – a network of Cancer Voices Cancer Voices Australia (CVA)

Say 'No' to gene patents – Sign our petition

US based company Myriad Genetics has retained the patent for exclusive licence to the BRCA1 gene in a court challenge by Yvonne D'Arcy and Cancer Voices Australia. On 15 Feb 2013 the Australian Federal Court ruled that the BRCA1 gene could be patented. See this informative [news item](#) or short video explaining the issue: [The 'Today' Show: A Gene Controversy](#).



This gene could be used to identify an increased risk of cancers in humans, but a gene patent means tests are controlled by Myriad Genetics. [Women with an altered BRAC1 gene](#) may have considerably increased chance of developing breast and/or ovarian cancer. Gene patents can control the cost of gene tests and restrict any 'second opinion' test. [Cancer Voices Australia](#) joins other cancer advocacy groups in protest against this.

We ask the Parliament to amend the Patents Act 1990 to clearly exclude the ability to grant patents over human genetic material (but without stifling innovations in the best interests of the community – [nbcf.org.au](#)).

Take action on this important issue.

Find out more, **sign the petition against human gene patents** online [here](#) and [download a form](#) to collect signatures.

Visit www.cancervoicesaustralia.org, and follow on  CVA [Facebook](#),  CVAT [Twitter](#)

Information

Boys join HPV vaccination program

Boys and girls aged 12-13 years will now receive the Human Papilloma Virus (HPV) vaccine at school (free of charge), following commencement of the world's first national HPV immunization program for boys on 15 Feb 2013. Boys aged 14-15 will also receive the vaccine until the end of the 2014 school year. New information about HPV and the vaccination program is available at www.hpvvaccine.org.au

Online training for Consumer involvement in cancer clinical trial groups

Cancer Australia has launched an [online multimedia learning resource for consumers](#) interested to be involved in cancer clinical trial groups. A series of slide sets and short videos explain how Clinical Trials are conducted, consumer roles in the cancer clinical trial groups supported by Cancer Australia, resources covering trial design, statistics, some practical tips and links to more information. There are 14 national Cancer Cooperative Trials Groups (CCTGs) in Australia. Check out the list and please get in contact if you are interested. The [Australasian Gastro-Intestinal Trials Group](#) is currently seeking additional representation on the Consumer Advisory Panel from Adelaide, Melbourne and Perth. <http://consumerlearning.canceraustralia.gov.au/>. Other groups may have vacancies.

Now what? A young persons guide to dealing with cancer

This guide has a wealth of useful tips, whether you are young, young at heart, or not so young. [Download the pdf](#) version and have a look through it. First published in 2011. <http://www.nowwhat.org.au/about/resources/now-what-a-young-persons-guide-to-dealing-with-cancer>



Consumer Engagement Toolkit

Cancer Australia has developed web-based practical tools to assist, **CEOs and Executives**, **Service Managers**, **Health Professionals**, **Researchers**, **Policy Makers** and **Consumers** to actively engage with consumers around a shared focus and vision in cancer control efforts. The Toolkit is based on the principles of the [National Framework for Consumer Involvement in Cancer Control](#). <http://consumerinvolvement.canceraustralia.gov.au/>

Towards meeting research needs of Australian cancer consumers

A collaboration led by Cancer Voices NSW and Cancer Council NSW has identified issues that cancer consumers would like researched, and describes the process they used to reach this consensus. Cancer consumers high priority research needs were found to be: earlier diagnosis of metastatic cancers; the extent of use of best practice palliative care guidelines; identifying barriers to cancer risk behaviour change; and environmental, nutrition and lifestyle risk factors for people with cancer. The full free text article is available at <http://www.biomedcentral.com/content/pdf/1756-0500-5-667.pdf>

Get Involved

Check out the Cancer Voices [Community NoticeBoard](http://www.cancervoicessa.org.au/awareness/community-noticeboard.html) to find out what's new or what's going on - at <http://www.cancervoicessa.org.au/awareness/community-noticeboard.html> . The Community NoticeBoard lists lots of events and **opportunities for cancer survivors to 'give back' and use their cancer experience** to help others. We encourage you to participate, in forums, surveys, focus groups etc.

Introduction to Consumer Advocacy run by Health Consumers Alliance (HCA) SA

This one-day training is free, runs from 9.30am - 3.30pm, includes morning tea and lunch and is held at Health Consumers Alliance, Level 1, 12 Pirie Street, Adelaide, SA 5000. Information includes: Consumers and consumer advocates, Introduction to Health Consumers Alliance, Partnering with consumers, State and national Health reform, Consumer participation in practice with experienced consumer advocate question and answer. Next training dates in 2013 are: **Wednesday 15 May, Thursday 15 August, Tuesday 12 November**. For more details contact Stephanie Miller sfmiller@hcasa.asn.au T: (08) 8231 4169 or visit the HCA website at <http://www.hcasa.asn.au/>

Colorectal Cancer and Influences on the Personal Impact of the Cancer Experience

Many Australians will experience colorectal cancer in their lifetime or will be in a long term relationship with someone who has. The experience is traumatic with the extent of distress experienced varying in response to many factors. Researcher Kristy Hodgson is interested in examining the nature of these factors so that we can develop mechanisms to support people following diagnosis. If you have experienced colorectal cancer in the past 15 years, or been in a relationship with someone who has, she would like to speak with you. Participation in the study involves completing a series of questionnaires that should take about 30 minutes. More information [here](#). Contact Kristy Hodgson on (08) 8313 5258, or email kristy.hodgson@adelaide.edu.au.

Cycling

Get fit and stay fit. Come along for a ride into the Hills with Cancer Voices SA cycling group. For information visit www.cvsacyclingteam.org.au. We start at 8am Sunday mornings from St Peters Girls College Car Park off Hallett Rd, Stonyfell, or join us for coffee and a chat afterwards at nearby Taylor Blend coffee shop on Hallett Rd, Stonyfell around 10.30am. (Next newsletter will feature our terrific [Cyclo-Sportif](#) teams, another CVSA cycling initiative.)



Cancer News

WATSON helps doctors treat cancer – sleuthing cancer treatment puzzles

[WATSON](#) is a computer application in the USA, developed by IBM partnered with WellPoint Inc and the Memorial Sloan-Kettering Cancer Center, to process, analyse and interpret complex clinical information. It aims to help raise the quality and efficiency of cancer care by processing huge amounts of evidence-based information (eg. the latest in cancer genetics research), in combination with an individual's clinical information from doctors and lab results. WATSON's program (called 'Interactive Care Insights for Oncology') produces an extensively cross-referenced series of answers with a confidence score to each answer ... and then it's up to the doctor to interpret and decide what to do next. Lung cancer is the first module available.

Find more about Cancer Voices South Australia at www.cancervoicessa.org.au

We welcome your involvement, feedback, any news or items of interest you wish to share.

Contact us at info@cancervoicessa.org.au

Follow our CVSA activities via  [Facebook](#)  [Twitter](#)  [Youtube](#)  [Flickr](#)

Best wishes from

Ashleigh Moore OAM (Executive) and the [Cancer Voices SA Executive Team](#)