



Cancer Voices SA

Raising a Voice for People Affected by Cancer

Annual Report 2020/21



Focussing on good systems, not just good luck, wellness – not just illness, and enabling our ‘lived experiences’ to shape the care and supports that people with cancer and those that care for us need now and into the future.



Cancer Voices SA is an independent, incorporated organisation of volunteers representing South Australians affected by cancer.
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Cancer Voices SA – 2020/21 in Summary

The purpose of Cancer Voices is to influence the achievement of **better outcomes for South Australians affected by cancer**. We provide a vital role in bringing the voice of the consumer to a broad range of **cancer services, policy and research**. The past 18 months has been profoundly different for any we have face thus far, but we have still come through with quite a lot achieved.

Our Executive Team members and supporters are involved in research activity that includes **ideas generation, concept development, input into grant applications, review of grant applications, building research/consumer relationships and engaging in the development of training resources for researchers working with consumers**. We also work with Cancer Voices NSW in providing a free service to researchers and research organisations to connect them with people who have successfully completed the ‘Consumer in Research’ Training. Requests for

our involvement in research initiatives continues to increase with our roles expanding to research co-supervisor, Associate Investigators and researcher partners. This reflects many years of building relationships and successful consumer advocacy and demonstrates the esteem in which our knowledge, experience and input is held in South Australia and nationally.

In 2020/21 we have also continued to build relationships with people affected by cancer; key cancer organisations; community organisations and policy makers; pursuing matters related to **safety; quality; access; equity; prevention; diagnosis; treatment and associated issues, follow-up care, palliative care training; digital technology in cancer health; and wellness**.

Our core programs, Survivors as Teachers, Sunday Cycling Team and Tuesday Walking Group continue to promote our focus on education and wellness, both physical and psychological, and are well supported by our members. Their commitment to a healthy lifestyle

and the discussions had during these programs about their lived experience, current research and cancer services, continues to be the foundation upon which our cancer advocacy work is built. Our newest walking group on Fridays - Consumers and Researchers Walk and Talk is flourishing in cross fertilisation of ideas and understanding.

The Westpac Foundation grant of \$10,000 awarded to us in 2019 for the rebuild of our website has yielded us a fruitful endeavour of a beautiful and functional



new site. We hope the launch of the new site will be the springboard our organisation needs to spread the workload amongst the executive team and improve our communication to our members. We are grateful to Westpac for their support.

As a 100% volunteer, not for profit organisation CVSA manages our governance arrangements mainly by email and teleconferences. All Executive Team members are volunteers and we require community donations and the sale of cycling gear to remain financial. We are indebted to those people who have given so generously. Without you we could not continue our work.



Vale Chris Christensen

Chris Christensen led Cancer Voices SA from 2017 until her death in Oct 2020, and we pay tribute to her contributions which built on the foundations established by Ashleigh Moore from 2007 - 2013. Organisations are more than individual leaders. The sustainability and capacity for maximising consumer involvement across the spectrum of treatment & care, in all aspects of research, policy and practice is still a 'work in progress'. More than 10 years of advocacy and action will be illustrated by our roles as change agents, policy influencers, community mobiliser, co-designers, research collaborators, educators and experts by experience.

CVSA Areas of Engagement and Influence

Cancer Voices SA Executive Team members and supporters are engaged and influence a range of South

Australian and Australian organisations. Team members are on a range of committees, working groups and advisory groups as well as presenting at conferences. In 2020/21 activities for engagement and influence included:

- **Ongoing involvement and membership as consumer reps**
 - PhD student Imogen Ramsey completed her studies in 2021 with Julie Marker as consumer co-Supervisor throughout this 3yr research study on ‘Population monitoring of survivorship in Australia – developing core outcome set for patient reported outcomes’ (photo)
 - SA Cancer Research Biobank - Governance Committee, Dr Eric Browne and Steph Newell
 - Consumer Engagement in health services, policy and research – multiple ongoing activities involving a number of the Executive Team
- The Australian, Vikki Bedford was interviewed for an article about Proton Therapy (photo)



- Multiple Grant application reviews by Karen Van Gorp, Julie Marker and Vikki Bedford
- Breastscreen SA meeting to discuss change in policy from 2019 to exclude women with medical device implants. Karen van Gorp and Vikki Bedford
- Board member – Melanoma Patients Australia – Karen van Gorp
- Ministerial Roundtable for the National Cancer Plan, CVSA consumer representative – Karen van Gorp
- World Cancer Day 2021 at Flinder’s University for sunrise yoga and contemplating our commitment to working together to imagine a world without cancer – Vikki Bedford
- Webinar Series Partnership with SAHMRI and the Australian Bragg Centre for Proton Therapy and Research: How can we improve the radiation experience for patients and families? With presenter Julie McCrossin – Vikki Bedford, interviewee and co-host
- Conference presentations:
 - Survivorship 2021 Conference –
 - Poster: What tools measure quality of life in paediatric cancer patients? A scoping review – Vikki Bedford
 - Poster: Survivors as teachers, helping students thrive despite COVID – Julie Marker and Cheri Ostroff
 - Poster: Consumer involvement in and impact on the development of a core outcome set for cancer survivorship – Julie Marker
 - Conference program committee and chairing several sessions of the virtual conference – Agnes Vitry
 - Presentation by CVSA members, Plenary: Neurotoxicity and neuropathy – Julie Marker, Finding my Feet
 - Ashleigh Moore Oration Award, Julie gave acceptance speech online but the award was given at a small gathering prior to the conference and Trevor was able to join us to celebrate (photo)

Cancer Voices SA Projects and Programs

CVSA core programs

- Cycling – Weekly Sunday rides and Annual Challenge Ride – **Thank you to Con Nakos**, and all who ride with us!
- Walking – weekly, Tuesdays in Belair National Park and our Friday Group (Consumers and Researchers - Walk & Talk) (photo)
- Chris' Walk – One Tuesday per month, our Belair walk includes researchers from Flinders University to join us in honour of Chris Christensen
- Survivors as Teachers program – leading and supporting tutorials involving University of Adelaide third year medical students
- Consumers in Research program – creating and supporting consumer engagement and opportunities

CVSA becomes involved in a range of projects as well as continuing to undertake our core programs. The range of projects and programs we are asked to participate in grows annually.

- Membership of the
 - SA Cancer Clinical Trials Network – Chris, Julie, Karen van Gorp
 - South Australian Cancer Research Biobanking Committee Members – Eric Browne and Steph Newell
 - nWCHN Consumer Advisory Group – Vikki Bedford
 - WCHN Chair of the Consumer and Community Advisory Committee – Vikki Bedford
 - WCHN Member of the Person and Family Centred Care Network – Vikki Bedford
- Presentations at the Survivorship Conference, COSA Conference

Research Related

- Ongoing active membership of Julie Marker in the Consumer Advisory Groups of the Australasian GastroIntestinal Trials Group AGITG, Primary Care Collaborative Cancer Clinical Trials Group PC4, and Psycho-Oncology Trials Group PoCoG
- Associate Investigators on numerous grants funded projects and grant applications
- Cancer Australia grant application submitted May 2021 for the category, Supporting People with Cancer – Idea is to develop a toolkit to reproduce “Survivors as Teachers” program – Julie Marker

Operations and Management

Our operations continue to be run as efficiently as possible and we are always grateful for any donations we receive. Thank you to all who have donated in 2020. We cannot survive without your support.

- Executive Team meetings and work mostly via teleconference and emails
- Website development and creation by Eric Browne
- Collaboration with Cancer Voices NSW
- Donation of a several items at Easter 2020, for fundraiser raffle (photo)
- Ongoing management of financial matters thanks to Julie Marker, Con Nakos, and Maurice Woolard for undertaking this role.



Vikki Bedford
Chair, Cancer Voices South Australia