

The Rules are posted on our website but it is important to outline our membership structure -

Membership will comprise eight (8) Voting Members each representing a State or Territory Cancer Voices, or in the absence of such a body, a cancer consumer organisation acceptable to the committee of Cancer Voices Australia.

The State and Territory Cancer Voices organisations will nominate one (1) person each to be Voting Members. A nomination should include the written consent of the nominee and the support of the executive of the relevant State or Territory Cancer Voices organisation, or a substitute organisation as referred to in Rule 2.

In addition to the membership, CVA will seek support for its activities through two reference groups:

- a) Specific cancer consumer groups including cancer support organisations, carer groups who will be invited to nominate to the Consumer Reference Group.

- b) Medical, scientific and health professionals from specific groups such as The Cancer Council Australia and its State and Territory members and the Clinical Oncological Society Australia who will be invited to join the Medical and Scientific Reference Group.

The Steering Committee are to be thanked for their input into the establishment of CVA. Its state member groups have elected representatives for the Board who will be ratified at the next meeting of CVA to be held in mid December.

CVA also has international links to CancerVoicesUK and CancerVoicesNZ.

### CVA with its strong consumer base is now advocating for:

1. Better access to services – for rural and remote patients
2. Access/availability to New Cancer Drugs
3. A more equitable share of the health budget for people affected by cancer

4. Consumer Representation
5. Patient Travel and Transport Schemes

CVA will work closely with Cancer Australia to assist where and when appropriate in its important role to improve the outcomes for those Australians affected by Cancer.

CVA recognises that cancer consumer and advocacy groups need to network. A major benefit in bringing groups together nationally is a means of identifying areas that will make a real difference to the burden of care for cancer patients, their families and carers.

### ACKNOWLEDGEMENTS

The Steering Committee would like to publicly acknowledge the contribution of CVA's inaugural Chair – Jane Cruickshank.

Jane was diagnosed with breast cancer in 1995, followed by a diagnosis of bowel cancer three years later (1998).

Jane became interested in the issues that she and her husband had faced and began researching the psycho-social issues that cancer survivors, their carers and families had to endure at this difficult time.

She and Ian appeared in the ABC Four Corners program entitled 'Surviving Survival', while working voluntarily with Professor Miles Little and his research team at Sydney University. Jane has co-authored research papers on survival after cancer and on cancer consumer representation.

As a founding member of Cancer Voices NSW, Jane helped to develop (and complete) the first Cancer Consumer Advocacy Training Course run in conjunction with The Cancer Council NSW in 2001.

Jane has developed an acclaimed reputation for her balanced viewpoint and collaborative approach to engagement with all key cancer stakeholders and sought to provide and enhance opportunities for increased awareness and understanding of the overall cancer patient journey. Her special focus brought about equal access and representation of people affected by all types of cancer to the attention of the cancer decision making authorities.

For family reasons Jane resigned from her position in May 2007.

We will miss her charm, her guile, her wonderful Scottish humour, and most of all, her balance and drive.

Thankyou Jane, for steering our first course and for being that wonderful 'voice' for cancer patients.

Providing great support to Jane during this period was Lisa Herron, who has a long association with Cancer Organisations. Lisa worked with CVA until June when she moved to Cancer Australia. Our thanks and best wishes go with Lisa to her new position.

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### CVA NEWSLETTER

Welcome to the official newsletter of Cancer Voices Australia.

### What is Cancer Voices Australia?

Cancer Voices Australia is a national consumer organisation representing Australians affected by cancer. It aims to ensure the voices of people affected by cancer are heard at a national level.

### WHAT'S IN A NAME?

Can you help CVA with a name for its Newsletter? Our logo contains of 8 moons or segments one for each of our member organisation. What do you think is an appropriate name?

Please send your suggestions to: john.stubbs@cancer.org.au

### OBJECTIVES

- To promote the fundamental rights of Australians affected by cancer
- To effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development, management and evaluation
- To promote the value and benefits of consumer participation in the development of national cancer policy and programs
- To provide a forum for member organisations to network and contribute to national activities

### WE WILL DO THIS BY:

- Identifying and advocating on issues of interest to people affected by cancer
- Enabling the voices of consumers to be heard, by nominating and supporting trained consumer representatives at a national level
- Increasing the number and diversity of people who have a voice
- Contributing to national policy by making submissions, participating in hearings, conferences and meetings, and seeking opportunities to collaborate with government and cancer organisations
- Encouraging member organisations to exchange information and ideas to contribute to national activities and to enhance their own advocacy efforts

### CONTACT US

Please feel free to contact CVA for an update of our work and priorities.

**Contact Details:** John Stubbs

P: 02 9036 0109

Cancer Voices Australia

F: 02 9036 0101

GPO Box 4708

E: john.stubbs@cancer.org.au

Sydney NSW 2001

W: www.cancervoicesaustralia.org.au

(Our website is currently under construction.)

- Promoting a balanced public awareness and understanding of all types of cancer and its impact on the community

- Seeking opportunities for and facilitating greater consumer involvement

- Encouraging research into areas of particular relevance to people affected by cancer

- Holding an annual meeting of member organisations and key advisers to determine priorities and review achievements and action.

## PURPOSE / VISION

Cancer Voices Australia provides a national, independent “voice” for people affected by all types of cancer, linking and collaborating with established advocacy groups, including Cancer Voices in NSW, ACT, WA and Victoria.

It will complement the activities of the national organisations representing people affected by a specific cancer.

CVA is committed to becoming a respected and integral part of the national cancer control arena, working collaboratively with its member organisations, the Federal Government, Cancer Councils, the Clinical Oncological Society of Australia and other clinical bodies and key stakeholders to improve

services and care for all people affected by cancer in Australia.

## INAUGURAL STEERING COMMITTEE

### David SANDOE OAM

Acting Chair CVA, Deputy Chair Cancer Voices NSW Board Member, Prostate Cancer Foundation of Australia

### Don BAUMBER

Gold Coast Prostate Support Group (Qld)

### Clive DEVERALL AM

CancerVoicesWA, Palliative Care (WA)

### Sally CROSSING AM

Chair, CancerVoices NSW, BCAG NSW

### Leonie YOUNG

CancerVoices QLD

### Ian ROOS

Chair, CancerVoices VIC.

### John JONGLING

Rep. TAS

### Denis STRANGMAN

CancerVoices ACT

### Executive Officer - John Stubbs

Together, the steering committee has over 50 years cancer consumer and advocacy experience and combined representation on 48 International, Federal, State and local Government boards and committees.

## BIOGRAPHIES

### David Sandoe OAM

(Acting Chair)

Diagnosed with prostate cancer 10 years ago David dedicates his spare time raising support, awareness and advocacy on cancer issues. He is co leader with his wife Pam of the Sydney Adventist Hospital Prostate Cancer Support Group. David is involved with chairing and directing on several Boards and Committees of the Prostate Cancer Foundation of Australia. He is also on the Executive Committees of Cancer Voices NSW, and the NSWOG Urology, a Director of the Institute for Magnetic Resonance Research, as well as part of the Members Assembly of CC NSW and the Executive Committee of the Australian Prostate Cancer Collaboration.

He was awarded an OAM in the 2006 Queen’s Birthday Honours for service to community health through support for men diagnosed with prostate cancer and their families, and to the insurance industry.

### Sally Crossing AM

Diagnosed and treated for breast cancer in 1995 and 2004, Sally founded the Breast Cancer Action Group NSW in 1997; a group with over 700 survivor members across the state, who provide a voice for people affected by breast cancer who want to ‘make a difference’.

Sally is also Chair of Cancer Voices NSW. Founded in 2000 and the first Cancer Voices in Australia, Cancer Voices NSW is a coalition of 80 cancer consumer groups which acts on behalf of the 34,000 people diagnosed with cancer in NSW each year.

At national level, she is a member of the Governing Committee of the Consumers’ Health Forum of Australia (CHF). Sally also acts as consumer representative on a number of committees at both state and national levels. In 2005 Sally was appointed a Member of the Order of Australia (AM) for services to the community through health care consumer advocacy and the establishment of the Breast Cancer Action Group NSW and Cancer Voices NSW. The NSW Minister for Fair Trading presented her with the inaugural Consumer Advocate Award in December 2001 for her work for women with breast cancer.

Initially trained as an economist, and after a career in banking and government, Sally now works full time on a voluntary basis to represent health care consumers.

### Denis Strangman

Following the death of his wife Margaret from a glioblastoma multiforme brain tumour, Denis works tirelessly as a consumer representative on ACT and national Palliative Care Committees and continues to advocate on behalf of Australians affected by Brain Tumours.

He was the Foundation Chair - Brain Tumour Australia 2003-005.

Elected Foundation Chair, - International Brain Tumour Alliance 2005 - to present.

### Don Baumber

Don is Co-chair of the Support and Advocacy committee of the Prostate Cancer Foundation of Australia (PCFA) representing around 80 independent Prostate Cancer support groups throughout Australia. He

also chairs the Queensland Chapter Council of Prostate Cancer Groups and represents Australian Prostate Cancer consumers through a position on the Board of PCFA.

### Leonie Young

Leonie was diagnosed with breast cancer in 1987,

She is involved with many aspects of breast cancer advocacy and support both nationally and internationally.

Leonie is the Peer Support Coordinator for the Wesley Hospital Kim Walters Choices Program in Brisbane, which offers support and information to women, men and their families who experience breast cancer.

### John Jongeling

John was born in the Netherlands in 1951 and migrated to Australia at an early age.

Diagnosed with NHL (what is this?) in 2002 and with a recurrence in 2004. John retains a positive spin on life.

In early 2005 he became involved with the Cancer Council in Tasmania and is now an active consumer representative for the Cancer Council and the Leukaemia Foundation in that state.

### Clive Deverall AM

After twenty years as Director of the Cancer Council of WA, Clive retired in 2000 following his cancer diagnosis.

A pioneer who helped set up domiciliary palliative care services in the early eighties

and later built Australia’s first free-standing, purpose built Hospice,

He was recognised with the Order of Australia (AM) in 2000 and later a Centenary Medal. Curtin University also awarded him an Honorary Doctorate of Letters for services to cancer patients and public education.

In addition to being a founder member of Cancer Voices WA, he continues as a consumer representative on various national and state committees including the NH&MRC, chairs the WA Government’s Charities Commission and facilitates three cancer support groups.

### Ian Roos

Ian is convener of Cancer Voices Victoria and is a volunteer with Cancer Connect and a consumer advocate. It is seven years since his diagnosis of prostate cancer.

Ian is a Senior Fellow in the Youth Research Centre at the University of Melbourne. With a background in medical research, related to the development of anti-cancer drugs, his research interests have remained in the health sector. However these interests have shifted with his career and have included: research in academia and at the Peter MacCallum Cancer Centre, a period as Dean of Whitley College, the Graduate School of Management at Monash University; and as a lecturer in management studies in the former Department of Education Policy and Management at the University of Melbourne.

### John Stubbs

John is 6 years post a Bone Marrow Transplant for Chronic Myeloid Leukaemia.

John is an active and vocal consumer for cancer patients and their issues both State and Federally.

He is the Executive Officer of Cancer Voices Australia and is currently working as a consultant to the Bone Marrow Transplant Network NSW.

He is member of the ANZ Clinical Trials Advisory Board; Board member of the Cancer Institute NSW; the ALLG Clinical Trials Data Monitoring Committee; the Therapeutic Goods Committee and other Federal and State Government working parties relating to cancer and cancer services throughout Australia.

## IN THE BEGINNING...

Many people affected by cancer acknowledge the need for a national group representing the voice, common interests and concerns of people affected by cancer in Australia.

In recognition of this need and interest, a meeting of representatives of the existing national (cancer type specific) and state/territory advocacy and consumer groups convened on 19 October 2005, hosted and supported by The Cancer Council Australia.

Participants unanimously agreed to establish a new organisation to identify and voice the common concerns and interests of people affected by cancer at a national level.

This organisation will work with national organisations representing people affected by a particular types of cancer, and state and /territory Cancer Voices organisations and other emerging consumer advocacy groups and networks.

An interim steering committee was formed committed to creating an organisation represented and accountable to people affected by cancer, providing an essential and independent “voice” but working in collaboration with relevant Federal and State Governments, Cancer Australia, allied health professionals COSA, Cancer Councils and cancer charities to improve cancer services and care in Australia.

CVA was formally incorporated on 29th September 2006.

