

# THE AUSTRALIAN CANCER CONSUMER NETWORK



## WHO'S WHO 2014



## Welcome to the Australian Cancer Consumer Network resource directory 'Who's Who 2014'

THIS IS AUSTRALIA'S FIRST NATIONAL DIRECTORY OF CANCER CONSUMER ORGANISATIONS.

We are pleased to be able to support the production of this first edition. The Who's Who has been collated by Cancer Voices Australia to connect Parliamentarians and their staff with relevant groups and services nationally. The information was provided by members of the newly formed Australian Cancer Consumer Network (ACCN).

Coordination of care for people with cancer, connecting with the right service at the right time, and understanding what services are available can all be unexpected and confusing obstacles for people in all stages of diagnosis and treatment. These groups know the issues and needs of people affected by cancer and advocate to make a real difference to the cancer 'journey'.

This directory is designed to enable Parliamentarians and their staff to provide up to date, relevant and timely information to people with cancer, their families and carers. It is the first of its kind and we plan to update it regularly.

Our heartfelt thanks go to Cancer Voices Australia for providing leadership and space to bring all of the groups together to form the Australian Cancer Consumer Network and create this wonderful ACCN resource directory – Who's Who 2014.

Yours sincerely,



Dan Tehan MP

Co-chairs Parliamentarians Supporting Cancer Causes



Senator Deborah O'Neill





# WHO'S WHO OF AUSTRALIAN CANCER CONSUMER GROUPS

Australian Cancer Consumer Network (ACCN)

The Australian Cancer Consumer Network brings cancer consumers group together to share information, experiences and issues. It currently numbers close to 30 groups and rising, covering many specific cancers and some generic cancer groups. Information about these follows.

The 'Directory' concept has been warmly welcomed by the Parliamentarians Supporting Cancer Causes, which launched this Who's Who in Canberra on 26 November 2014. Co-host was Cancer Voices Australia, the independent volunteer voice of Australians affected by cancer, which currently facilitates the ACCN.

Compilation of this Who's Who acknowledges twenty years of cancer consumer advocacy in Australia (1994 – 2014). It also honours the establishment of the ACCN this year.

Now people affected by cancer - we consumers of cancer services, policy and research - can more effectively work together. We can provide informed input to national agendas, like those of the PBAC and MSAC, and to cancer related inquiries and committees. Most importantly we can muster a louder voice on national issues if and when necessary. And you, gentle reader, can now find and talk to us with ease.

Thanks go to the Parliamentary Friends, especially Co-Chairs Dan Tehan MP and Senator Deborah O'Neill, who have enthusiastically encouraged and supported this first edition. We look forward to a long and productive relationship with Members of Parliament and Senators who have an interest in cancer and in our "essential perspective".

## **WE ARE NOT ALL THE SAME**

Within the ACCN there are a range of groups: some for specific cancers, others generic, and with varying kinds of consumer governance, representation and independence. Some offer information, some support, some advocacy through the consumer view, some promote awareness and some do all these things. We decided to be as inclusive as possible, while asking entrants to note these differences.

Groups range from fully independent 100% volunteer cancer consumer groups with no government or industry funding and whose key purpose is advocacy for people affected by cancer. Some other independent groups have more traditional corporate structures and may receive government funding for projects and actively raise their own funds.

Other models are found in the charitable cancer organisations, foundations and some research institutes which have set up Consumer Advisory Groups for advice on their own information, support, research and advocacy. Sources of funding may also be useful to know: is the consumer group or parent organisation supported by community donors, by government or industry funding and to what extent? We have asked the groups in these pages to provide information about these all these aspects, but if you need more, just contact them directly.

## THE FUTURE

This Who's Who, being the first of its kind, will expand as more groups and organisations develop and join in. It will be updated regularly and will be posted online in 2015. We value feedback to make this resource better – let us know your views via [info@cancervoicesaustralia.org.au](mailto:info@cancervoicesaustralia.org.au).

Enjoy discovering us when you would like to hear the voices of Australians affected by cancer!



**Sally Crossing AM**  
**Convenor, Cancer Voices Australia**  
**November 2014**



## CANCER VOICES AUSTRALIA

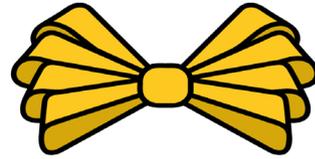
Cancer Voices Australia (CVA) is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard. Cancer Voices has led the generic cancer consumer movement in Australia since 2000. The CVA network works together on national issues identified as important by people affected by cancer, with consumers working to help others like themselves.

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# The Australian Thyroid Foundation Ltd



The Australian Thyroid Foundation Ltd. (ATF) was founded in 1995 by Gail Ballantyne - a thyroid cancer patient - with a small group of people with different thyroid disorders who wanted to provide support and educational services to members and their families.

Today the ATF is a national not-for-profit organisation with charity status.

The ATF is funded mainly by membership fees, donations and some sponsorship from pharmaceutical companies. The ATF presently does not receive any government funding or assistance.

The ATF's focus is to support and educate its strong member base and promote our good thyroid health and iodine deficiency awareness messages throughout the Australian Community.

The ATF is a company limited by guarantee under Australian law. The organisation is headed by company directors and committee, who are all members of the organisation and are responsible for the day to day running of company business under the company constitution. The directors of the company are responsible to the Australian Taxation Office (ATO), The Australian Charities and Not-For-Profit Commission (ACNC) and the Australian Securities and Investment Commission (ASIC) The ATF hold ABN 28 080 557 642.

All positions held by company directors, medical advisors and staff are all held by volunteers.

The ATF is recognised by The Food Standards of Australia and New Zealand (FSANZ) as the consumer advocacy organisation for iodine deficiency and thyroid disorders.

The ATF is proud to have Professor Creswell Eastman AM as it's patron and Principal Medical Advisors, Professor Bruce Robinson and Professor Leigh Delbridge as Chief Medical Advisors.

The ATF is a member of Thyroid Federation International (TFI), a world-wide thyroid patient organisation dedicated to global action on thyroid related issues.

**Mission:** To offer support, information and education to members and their families through the many services provided by the ATF and raise awareness about health consequences of iodine deficiency and the benefits of good thyroid health.

## **AIMS AND VISIONS**

Prevention, Education, Continual Upgrade of ATF Member Services

Awareness of the Benefit and Importance of Achieving Good Thyroid Health through an Australia-wide educational program, jointly working with selected sponsors/partners to educate the community about the benefits of good thyroid health with proper diagnosis, treatments and medications.

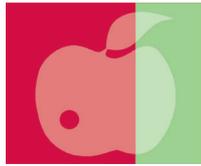
Raise awareness to help overcome iodine deficiency through awareness and education of the importance of iodine enriched food choices and ways to achieve adequate iodine levels through different life stages.

To co-operate and collaborate with healthcare professionals in supporting and treating patients with thyroid disorders, including thyroid cancer.

To lobby governments for funding and support to help increase awareness of thyroid disorders, thyroid cancer and iodine deficiency

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Mobile: 0416 269 982  
Address: Suite 2 Melville Street, Parramatta NSW 2150  
Tel: (02) 9890 6962  
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Email: [Info@thyroidfoundation.com.au](mailto:Info@thyroidfoundation.com.au)  
Website: [www.thyroidfoundation.com.au](http://www.thyroidfoundation.com.au)  
Facebook: [www.facebook.com/pages/Australian-Thyroid-Foundation/13419335753](https://www.facebook.com/pages/Australian-Thyroid-Foundation/13419335753)  
Twitter: [www.twitter.com/austhyroidfdn](https://www.twitter.com/austhyroidfdn)





# Bowel Cancer Australia

Bowel Cancer Australia has a vision to reduce incidence, death and suffering associated with bowel cancer through advocacy, awareness, education, support and research.

Founded in 2000, Bowel Cancer Australia is the only national charity that works across the entire bowel cancer spectrum.

Bowel Cancer Australia is the leading voice of the bowel cancer community, driving ongoing access to evidence-based, high quality programs, services and treatments that deliver better patient outcomes.

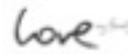
The charity is driven by a small team of staff and volunteers, receiving no government funding and relying solely on donations to continue our life saving work. We thank our many enthusiastic fundraisers, corporate partners and supporters across the country for their generosity. Every donation makes a real difference.

Your support of Bowel Cancer Australia not only helps to save lives, but also to improve the health and wellbeing of people living with bowel cancer.

Address: Level 2, 65 Walker Street NSW 2060  
Tel: 1800 555 494 or 02 9923 8269  
Fax: 02 9923 8290  
Email: [info@bowelcanceraustralia.org](mailto:info@bowelcanceraustralia.org)  
Website: [www.bowelcanceraustralia.org](http://www.bowelcanceraustralia.org)  
Facebook: [www.Facebook.com/BowelCancerAustralia](http://www.Facebook.com/BowelCancerAustralia)  
Twitter: [www.Twitter.com/BowelCancerAust](http://www.Twitter.com/BowelCancerAust)  
Instagram: [www.Instagram.com/BowelCancerAustralia](http://www.Instagram.com/BowelCancerAustralia)

Key Bowel Cancer Australia advocacy contacts:

**Julien Wiggins (Chief Executive Officer) and Claire Annear (National Community Engagement Manager).**





# BRAIN TUMOUR ALLIANCE AUSTRALIA INC.



Raising the public's and decision maker's awareness of personal and population-level impacts of brain tumours.

Providing support and information services to patients, their caregivers and families. Advocating for funding of brain tumour care coordinator positions. BTAA is an umbrella group for a number of brain tumour related organisations. It convenes a national summit of groups.

Operations: Maintaining a website of relevant information ([www.btaa.org.au](http://www.btaa.org.au)); Providing a Freecall 1800 number (1800 857 221) staffed by a trained counselor (nearly 500 calls a year); Distributing free of charge, authoritative medical information booklets. Hosting patient and caregiver information days around Australia; Providing education grants to health professionals.

Structure: Volunteer led, funded by public (non-government only) and industry donations. Incorporated under the Associations Incorporations Act 1991 in the ACT, with seven office-bearers (listed above), approximately eighty financial members and a mailing list of over 1,200 supporters.

Additional: Founded in 2008. BTAA enjoys a good working relationship with the Parliamentary Brain Tumour Awareness Group, co-convened by Senators Catryna Bilyk and Scott Ryan. Turnover in 2013-14 of \$115K.

Key personnel: Volunteer committee comprised of Matt Pitt (Chair), Kelly Webster (Vice Chair), Catherine Hindson (Treasurer), Susan Pitt (Secretary), Denis Strangman (Public Officer), MaryAnne Rosier (Fundraising & Support), Mark Dalliston (Consumer Liaison). No paid staff.

Address: PO Box 76, Dickson, ACT, 2602.  
Tel: 1800 857 221  
Email: [enquiries@btaa.org.au](mailto:enquiries@btaa.org.au)  
Website: [www.btaa.org.au](http://www.btaa.org.au)  
Twitter: BrainTumourAA  
Facebook: Brain Tumour Alliance Australia (BTAA)



# BREAST CANCER ACTION GROUP NSW

The Breast Cancer Action Group NSW is the independent voice of people affected by breast cancer in NSW. Since 1997 we have provided the consumer perspective in decision-making to improve information about breast cancer and to improve its diagnosis, treatment, care, support and research.

## WHO ARE WE?

BCAG NSW members are people affected by breast cancer across NSW. We are all volunteers with personal experience of breast cancer who are interested in being informed and in making a difference. We are of all ages and include networks for younger women, rural women and women with metastatic breast cancer.

Our representatives present a broad, informed view on issues affecting people affected by breast cancer, mainly at state level.

## WHAT DO WE DO?

- Seek and promote sources of good information
- Listen to and collate the needs and views of people affected by breast cancer
- Ensure the consumer view is heard
- Work in partnership with stakeholders in the breast cancer world
- Provide an informed voice at decision-making tables and for the media
- Write submissions, appear before inquiries, speak at conferences

## SOME ACHIEVEMENTS

- Published the Directory of Breast Cancer Specialists in NSW 2002
- Designed a Directory of Lymphoedema Specialists (now developed by ALA)
- Published "Women for Women with Breast Cancer 1997-2007"
- Achieved legislative change for access to superannuation for the terminally ill
- Influenced scope of data collection
- Hosted a series of "Women for Women" Information and Advocacy Forums
- Nominated and supported informed representatives to work with major service providers, research funders and organisations, local breast cancer clinics, professional colleges, government & Senate Inquires
- Published quarterly 24-page newsletters 1997-2012
- Contributed to community & media debate related to breast cancer

Funding: BCAGNSW is fully independent of government or industry funding  
Structure: 1997-2014 an Incorporated Association (NSW); now operating under the umbrella of Cancer Voices NSW.

Contact: Roberta Higginson, Chair  
Tel: 0411 466 986  
Email: robertahigginson@optusnet.com.au  
Website: www.bcagnsw.org.au (under reconstruction)



# BREAST CANCER NETWORK AUSTRALIA



Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer, and consists of a network of more than 95,000 individual members and 300 Member Groups.

BCNA supports, informs, represents and connects Australians affected by breast cancer.

We collaborate with governments and health professionals to deliver programs and services to people who need our support. For example, BCNA's evidence-based resource, *My Journey Kit*, contains comprehensive information for newly diagnosed women, and reaches 83% of all women diagnosed with breast cancer in Australia.

BCNA is funded by community donations, sponsorships and government contributions. We currently employ around 40 staff members who are supported by 45 volunteers and 270 Community Liaisons (women who represent BCNA within their local communities).

For more information about BCNA and the services and programs we deliver, visit our website: [www.bcna.org.au](http://www.bcna.org.au).

Contact: Kathy Wells, Policy Manager  
Email: [kwells@bcna.org.au](mailto:kwells@bcna.org.au)  
Tel: 1800 500 258 or (03) 9805 2562  
Address: 293 Camberwell Rd Camberwell VIC 3124  
Website: [www.bcna.org.au](http://www.bcna.org.au)





## **CANCER ACTION VICTORIA**

Cancer Action 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. We want to ensure that the voices of patients and those affected by cancer are being heard in policies and programs for the prevention, diagnosis, treatment, survival issues and research in the area of cancer.

Contact: Dr Pamela Williams OAM, Hon Secretary  
Mail: PO Box 2286, Mt Waverley Vic 3149.  
Email: [canceractionvictoria@gmail.com](mailto:canceractionvictoria@gmail.com)  
Tel: 03 9807 8480





CUP Action is an information and support organisation for those affected by cancer of unknown primary (CUP), a little known but surprisingly common form of cancer which is in the top 10 causes of cancer deaths in Australia.

The organisation was founded in 2010 by Jane Barrett, who had been diagnosed with CUP the previous year.

Her efforts were instrumental in bringing wider recognition in the medical community and in the general population of the devastating impact of this form of the disease. Jane died in 2012 but her website [www.actiononunknownprimary.org](http://www.actiononunknownprimary.org) remains as a resource for patients and carers.



## CANCER VOICES ACT



Wahlenbergia gloriosa

**Objectives:** Cancer Voices ACT representative contribute to decision-making by representing the needs and interests of people affected by cancer in the ACT and beyond by working with Cancer Voices NSW.

**Operations:** Raising the ACT public's and decision maker's awareness of personal and population-level impacts of cancers. Providing support and information services to patients, their caregivers and families. Advocating for funding of brain tumour care coordinator positions. Umbrella group for a number of brain tumour related organisations. Convenes a national summit of groups.

**Structure:** An alliance of cancer advocates active in the ACT. They include but are not limited consumer advocates active in breast cancer ( Breast Cancer Network Australia, Bosom Buddies, Dragons Abreast), the Prostate Cancer Foundation, the Leukemia Foundation and Brain Tumour Alliance Australia (the ACT Brain Tumour Network. Some are members of Cancer Voices NSW. Some are active in the Health Care Consumers Association of the ACT to represent the views of cancer consumers.

**Contact:** Susan Pitt, Cancer Voices ACT Liaison  
**Address:** PO Box 76, Dickson, ACT, 2602.  
**Phone:** 0404255156.  
**Email:** susan.pitt@netspeed.com.au  
**Website:** <http://www.cancervoices.org.au/contact-us/>





## cancer voices **australia**

Cancer Voices Australia is the independent, volunteer voice of people affected by cancer since 2000, working to improve the cancer experience for Australians, their families and friends.

We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

### **WHAT WE DO**

Cancer Voices Australia can provide:

- informed cancer consumer views on national issues;
- representatives to participate on national level decision-making committees; and a matching service to link stakeholders with appropriate consumer representatives.

Cancer Voices Australia currently facilitates the Australian Cancer Consumer Network which links 29 cancer consumer organisations, some generic and others cancer specific.

Cancer Voices Australia's website address is [www.cancervoicesaustralia.org](http://www.cancervoicesaustralia.org)

The website posts our two-monthly NEWS UPDATES, submissions to national inquiries and Position Statements developed with our network and offering the consumer view on major national level issues.

Please use the website's online forms to request a trained, informed consumer nominee for your policy, service provision or research committee / project.

CVA is independent of Government or industry funding

Contact: Sally Crossing AM  
Email: [info@cancervoicesaustralia.org.au](mailto:info@cancervoicesaustralia.org.au)  
Tel: 02 9436 1755  
Mail: PO Box 5016 Greenwich NSW 2065  
Facebook <https://www.facebook.com/CancerVoicesAustralia>  
Twitter @CancerVoicesAu





Cancer Voices NSW provides the peak, volunteer and independent voice of people affected by cancer, working to improve the cancer experience of the over 40,000 people who are diagnosed each year in our state. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services and policy makers, ensuring the patient perspective is heard.

## **ACTIVITIES SUPPORTING THE VOICES**

### **TRAINING FOR CONSUMERS**

In conjunction with the Cancer Council NSW, Cancer Voices offers short training courses in representation, advocacy and research for interested consumers. Graduates are offered positions on stakeholder committees and working parties to provide the broad cancer consumer view.

The Consumer Involvement in Research Program matches and links informed, trained consumers with researchers seeking their input to cancer research studies and projects. Many cancer funding organisations now require evidence of consultation with consumers. Researchers may request help through the CVN website.

### **SPEAKING OUT**

Cancer Voices NSW makes invited presentations to conferences and cancer related events about issues for people affected by cancer. We also provide articles, media comment and make submissions to cancer related inquiries.

### **COMMUNICATIONS**

Quarterly newsletters for members and interested stakeholders are mailed and posted on the CVN website. Members' views and issues are sought on a regular basis to inform our efforts on behalf of people affected by cancer. We published "A Decade of Success: Cancer Voices NSW 2000-2010".

### **STRUCTURE**

Cancer Voices NSW is an Incorporated Association within NSW, and is managed by an Executive Committee. Voting members are cancer support and advocacy groups, of which there are around 80. Individual membership numbers: 400.

### **FUNDING**

Cancer Voices NSW is fully independent of either government or industry financial support. While membership is free, many members and friends support us through donations. All our work is undertaken by volunteer members who contribute their skills, enthusiasm and commitment.

Website: [www.cancervoices.org.au](http://www.cancervoices.org.au) includes newsletters, position statements, news, opportunities to participate, electronic forms for membership and for stakeholders seeking consumer nominees.

Chair: Sally Crossing AM  
Email: [info@cancervoices.org.au](mailto:info@cancervoices.org.au)  
Tel: 02 9436 1755  
Mail: PO Box 5016 Greenwich NSW 2065  
Facebook: CancerVoicesNSW





We are people affected by cancer, all types & stage of cancers across all ages, social circumstances, gender and locality in South Australia.

We 'raise a voice' through advocacy, involvement, awareness and information. We work at the system level for 'people affected by cancer' to have an effective voice in all aspects of decision-making about cancer, including treatment, care, system design, support, planning, teaching, research and prevention.

Our focus is on wellness and not just on illness.

We are an independent, not-for-profit, 100% volunteer organisation, formed in 2007. We are a member of Cancer Voices Australia, Consumers Health Forum of Australia and Consumers Health Alliance of South Australia.

Membership (currently about 800) is free and open to cancer patients, their partners, carers, family, friends, neighbours, colleagues and supporters.

Key achievements – 'Patients as teachers' educational initiative, Cancer Voices Cycling group, consumer reps on state & national committees, eBulletins informing consumers of events, activities & news.

Acting Chair: Julie Marker; ph 08 8332 5527  
Address: PO Box 588 Kensington Park SA 5068  
Email: [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au)  
Web: [www.cancervoicessa.org.au](http://www.cancervoicessa.org.au) & [www.cvsacyclingteam.org.au](http://www.cvsacyclingteam.org.au)

Facebook: [www.facebook.com/CancerVoicesSA](http://www.facebook.com/CancerVoicesSA)  
Twitter: @CVSAinfo  
Scoop: [www.scoop.it/t/cancer-advocacy-by-cancer-voices-sa](http://www.scoop.it/t/cancer-advocacy-by-cancer-voices-sa)  
Youtube: [www.youtube.com/cancervoicessa](http://www.youtube.com/cancervoicessa)  
Flickr: [www.flickr.com/photos/cancervoicessa/sets](http://www.flickr.com/photos/cancervoicessa/sets)





CanTeen supports young people when cancer turns their world upside down and helps them cope with the physical, emotional and practical impact of living with cancer.

We provide funding for specialist hospital care, counselling online and face to face, individual assistance by social workers as well as information and peer support programs for 12-24 year-olds affected by cancer. This includes their own diagnosis or that of a parent or sibling or the death of a parent or sibling from cancer.

CanTeen was established by a group of young cancer patients in 1985 and we continue to be a Member-led organisation where young people affected by cancer provide direction, feedback and advice at every level of the organisation.

Donations from individual supporters form 69% of CanTeen's income with Australian Government funding providing an additional 14% and the rest from community fundraising, corporate partnerships and foundations such as the nib foundation, a major sponsor.

Our 2012/13 Annual Report is available here:

<http://www.canteen.org.au/about-us/canteen-today/annual-report/>

Australian Government funding has been and continues to be vital in the delivery of two key CanTeen services:

- **Youth Cancer Services:** The Youth Cancer Services (YCS), managed nationally by CanTeen with Australian Government funding, operate in major hospitals across the country and are the only place in Australia providing specialist treatment and support for young people (aged 15-25) diagnosed with cancer.

- **CanTeen's Online Support Platform:** launching Oct 2014 ([www.canteen.org.au/nowwhat](http://www.canteen.org.au/nowwhat)) Developed by CanTeen with funding from the Australian Government, CanTeen's Online Support Platform sets an international benchmark with its world first combination of 7-day access to professional CanTeen counsellors and 24/7 access to youth-specific information and an online community where young people can connect with peers in similar situations and share their cancer experiences through blogs, forums and testimonials.

CEO: Peter Orchard  
Phone: 1800 226 833  
Email: [support@canteen.org.au](mailto:support@canteen.org.au)  
Website: [www.canteen.org.au](http://www.canteen.org.au)  
Twitter: [www.twitter.com/CanTeenAus](http://www.twitter.com/CanTeenAus)  
Facebook: [www.facebook.com/CanTeenAus](http://www.facebook.com/CanTeenAus)  
YouTube: [www.youtube.com/CanTeenAustralia](http://www.youtube.com/CanTeenAustralia)



# DRAGONS ABREAST AUSTRALIA



Dragons Abreast Australia is a national organisation comprised of breast cancer survivors (and supporters) of various ages from a great variety of backgrounds, athletic abilities and interests. Dragons Abreast members provide a “face” for the breast cancer statistics whilst spreading the message of breast cancer awareness through participation in the wonderful and strenuous sport of dragon boat racing.

## **AWARENESS, PARTICIPATION, INCLUSIVENESS**

### MISSION:

Encourage wellness, fitness, fun and camaraderie for breast cancer survivors through the sport of dragon boating and promote breast cancer awareness throughout our community.

### VISION:

Dragons Abreast is a leader in the movement for people affected by breast cancer; spreading awareness, empowering individuals, and educating on the benefits of an active lifestyle after diagnosis.

### STRUCTURE:

A national breast cancer survivor led organisation, independently funded by donations and fundraising activities. The organisation unites and supports 35 DA member groups (1600 members) located in city and rural locations across Australia. Our major fundraiser is the Dragons Abreast Festival held annually in Sydney. The organisation employs 2 paid part time staff to run the office but runs mainly on with the time and expertise of volunteers.

Address: PO Box 380, Cannon Hill, QLD, 4170  
Phone: 1300 889 566  
Email: [office@dragonsabreast.org.au](mailto:office@dragonsabreast.org.au)  
Website: [www.dragonsabreast.com.au](http://www.dragonsabreast.com.au)  
Chairperson: Sue Bowen [chair@dragonsabreast.org.au](mailto:chair@dragonsabreast.org.au)





GASTRO-INTESTINAL CANCER RESEARCH

Gastro-Intestinal (GI) cancer includes cancers of the oesophagus, gallbladder, liver, pancreas, stomach and bowel (the bowel includes the small intestine, large intestine or colon and rectum) and together are the most common form of cancer in Australia.

The GI Cancer Institute Consumer Advisory Panel has developed the Engage Program to disseminate information about GI cancer prevention, screening, support, services and research; and evidence based information about the latest GI cancer treatments. The Engage Program is a Cancer Australia Supporting people with cancer grant initiative, funded by the Australian Government.

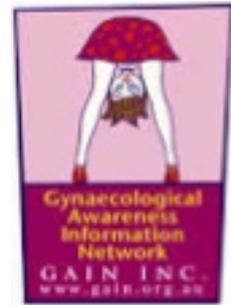
The GI Cancer Institute Consumer Advisory Panel consists of GI cancer survivors and carers from across Australia. All the GI cancer types are represented on the Panel.

Engage Community Forums bring together people living with or an interest in GI cancer and their families and supporters together with support networks, service providers, researchers and clinicians, in a supportive environment, to develop and enhance linkages in local communities, improving access for consumers by bringing stakeholders together in a 'one stop shop' format.

Organisation: GI Cancer Institute  
Key contact: Russell Conley, Executive Officer  
Postal address: Locked Bag 77, Camperdown NSW 1450  
Phone: 1300 66 67 69  
Email: [info@gicancer.org.au](mailto:info@gicancer.org.au)  
Website: [www.gicancer.org.au](http://www.gicancer.org.au)



# GYNAECOLOGICAL AWARENESS INFORMATION NETWORK (GAIN)



GAIN Inc. is a not-for profit consumer organisation run by volunteers.

GAIN Inc. is funded solely by donations and grants.

GAIN Inc's primary objectives are to:

- Engage and involve the community by advocating for the promotion of gynaecological and sexual health;
- Bridge the gap between the health professionals and the community;
- Empower women to be actively and confidently involved in their gynaecological and sexual healthcare;
- Working to reduce the stigma associated with gynaecological health and associated conditions.

Over the past 12 months GAIN Inc. has redirected its focus to provide information, promote awareness and open dialogue on women's gynae health issues using social media platforms, namely Facebook and now Twitter.

GAIN Inc. will continue to provide ongoing support to women affected and suffering with gynae health issues and can be reached via our contact details. GAIN Inc. in conjunction with the Health Organization for Pudendal Education (HOPE) run a support group every second Saturday of each month in Perth, WA for individuals suffering from chronic pelvic pain and pudendal neuralgia (PN).

Contact: Tina Schiavello, PhD  
Mail: PO Box 170 Subiaco, Western Australia, 6904  
Email: [enquiries@gain.org.au](mailto:enquiries@gain.org.au)  
Web: [www.gain.org.au](http://www.gain.org.au)  
Facebook: [www.facebook.com/pages/GAINInc/441517922555628?fref=ts](https://www.facebook.com/pages/GAINInc/441517922555628?fref=ts)





“Unlike adult cancers where risks can be modified through lifestyle changes like quitting smoking or losing weight, there are no such risk factors for childhood cancers. That means that a child’s prognosis can only be improved through research advances.”

Professor Peter Smith, Dean UNSW Medicine, Chairman Research Advisory Council TKCP

## **INTRODUCTION**

The Kids’ Cancer Project is an independent Australian charity that funds childhood cancer research and provides information to families about trials and treatments available. Col Reynolds, OAM, who is a former tour coach driver, founded the charity in 1993.

Our strategic direction is guided and driven by the needs of families. Our understanding of the issues of childhood cancer is drawn from the real life experiences of children, parents and the short and long-term impacts they experience.

### **Supporting Children, Parents and Families**

In addition to supporting research we guide families in seeking treatment options for their child. Parents and families are faced with daunting decisions while their child is being treated for cancer, which they are mostly unprepared for. We support these parents in overwhelming times with knowledge and information drawn from a unique position of responsibility.

We use our experience and relationships to call on local and global partners plus networks of clinicians and researchers to guide and give hope.

### **No prevention = Medical Research**

We support research in areas of greatest impact with the ultimate goal of bringing about 100% survival in children while minimising the harmful effects of treatment. Equal to our research priority is supporting parents and families during their child’s cancer journey.

Support is not enough. We understand to really make an impact and save children’s lives medical research needs to be funded and championed.

Thanks to over 1.2 million Australians supporting TKCP we have funded over \$24 million in research in the last 10 years including in excess of \$3.6 million in 2014. Our approach to research works. We currently support 11 projects across various institutions in Australia.

### **Contact us:**

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T +61 2 8394 7777 | [www.thekidscancerproject.org.au](http://www.thekidscancerproject.org.au)





# LUNG FOUNDATION

AUSTRALIA

*"When you can't breathe... nothing else matters"*<sup>TM</sup>

Lung cancer is the fourth most commonly diagnosed cancer and the biggest cancer killer in Australia. More than 22 people die each day from Lung cancer – that's more than breast, ovarian and prostate cancers combined. The economic and social burden of lung cancer is high. Survival is low.

Lung Cancer Network Australia (formerly Kylie Johnston Lung Cancer Network) is an initiative of Lung Foundation Australia. Lung Cancer Network Australia (LCNA) aims to empower lung cancer patients, their families and carers with reliable information, support and advocacy, no matter who they are and where they live. Lung Foundation Australia is a National not for profit organisation that is focused on making lung health a priority for all in Australia.

The LCNA works to:

**INFORM** We develop and distribute free, reliable and up to date information about lung cancer specifically designed to meet the needs of lung cancer patients and their families. We work to raise the profile of lung cancer in the community as part of promoting lung health as a priority for all Australians.

**CONNECT** We encourage patients and their families to connect with one another through telephone and face to face support groups, our on line forum, and other web-based technologies so that they might share experiences and offer one another hope, inspiration and understanding – from anywhere in Australia.

**EMPOWER** We encourage patients and their families to be proactive in their ongoing treatment and care and establish strong relationships with their GP and lung cancer specialists so that they can access the best multi-disciplinary care to get the right treatment at the right time.

**REPRESENT** We work in partnership with other cancer organisations and health organisations to develop or update patient resources, guidelines for health care professional and to educate the community on the possible symptoms of lung cancer so that early detection will take place.

**FUNDRAISE** We encourage people to participate in fundraising activities

LCNA Advocates for:

Lung cancer patients in Australia have equitable access and rapid referral to a specialised lung cancer multidisciplinary team (MDT), which for optimal coordination of the lung cancer pathway from symptom investigation onwards must include a specialised nurse. We know lung cancer patients who are diagnosed and cared for by these multidisciplinary teams can have improved survival rates and quality of life.

Key Contact Details:

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Glenda Colburn, Director – LCN Program. Email: [Glenda@lungfoundation.com.au](mailto:Glenda@lungfoundation.com.au)

Address: Lung Foundation Australia Information and Support Centre  
Level 2, 11 Finchley Street, Milton QLD 4064

Freecall: 1800 654 301

Phone: 07 3251 3600

Fax: 07 3368 3564

Website: [www.lungfoundation.com.au](http://www.lungfoundation.com.au)

Facebook: <https://www.facebook.com/lungfoundation>

Twitter: <https://twitter.com/Lungfoundation>

Youtube: <https://www.youtube.com/user/thelungfoundation>

Instagram: [@Lungfoundationaustralia](https://www.instagram.com/Lungfoundationaustralia)



# LYMPHOEDEMA ACTION ALLIANCE



Lymphoedema is the term given to swelling resulting from malfunction of the lymphatic system. It can affect people of all ages, whether it is as a result of underdeveloped lymphatics, or due to damage to the lymph system from cancer treatment. Cancer treatment is the leading cause of lymphoedema in Australia.

The Lymphoedema Action Alliance is made up of 15 organisations.

The Alliance is working to reduce the unnecessary suffering of people who have lymphoedema, by ensuring timely access to affordable lymphoedema services, regardless of where people live, their financial status and their health situation.

Website: [www.actionalliance.org.au](http://www.actionalliance.org.au)

Contact: [info@actionalliance.org.au](mailto:info@actionalliance.org.au)

## **MEMBERS OF THE LYMPHOEDEMA ACTION ALLIANCE:**

Australasian Lymphology Association  
International Lymphoedema Framework Australia  
Breast Cancer Action Group  
Breast Cancer Network Australia  
Cancer Action Network Northern Suburbs  
Cancer Council NSW  
Lymphoedema Support Group NSW  
Macquarie University Cancer Institute  
Lymphoedema Training and Education NSW  
Ovarian Cancer Australia  
Melanoma Patients Australia  
YWCA Encore Program NSW  
Australian Association of Massage Therapists  
Country Women's Association NSW  
Lymphoedema Practitioners Education Group of Victoria





## **RAISING AWARENESS GIVING SUPPORT SEARCHING FOR A CURE**

Lymphoma Australia was established in 2004 to support lymphoma patients and their families, build awareness in the community and raise funds to support research for a cure. Initially started as a support group in the Gold coast, since its creation Lymphoma Australia has grown into a nationwide organisation.

Our major projects and initiatives include; the creation and distribution of complementary resource materials to all new patients, the management of lymphoma education days in hospitals across Australia which stream online, advocacy for patients to access new treatments and clinical trials. Alongside this we campaign for greater awareness of lymphoma in order to decrease the number of people lost to this silent cancer due to late or miss-diagnoses.

Lymphoma is diagnosed every 2 hours and every 6 hours a life is lost to lymphoma - with your help we can change this.

## **OVERALL STRUCTURE**

Lymphoma Australia is overseen by a volunteer board of clinicians, health professionals, business people and lymphoma advocates. The operation of the organisation is led by 2 staff and a team of volunteers in different states in Australia. The majority of funds for our work to date has been from community fundraising activities.

## **KEY ISSUES**

Lymphoma is a complex cancer with main subgroups but with more than 60 different subtypes. Outcomes vary depending on the type of lymphoma and this can include very aggressive with a poor outcome, slow growing but incurable and potentially curable. Due to low community awareness this disease is often diagnosed late despite it being our sixth most common cancer.

Men and women are equally affected and children are not immune to this cancer. With no known cause and therefore no prevention measures we are keen to make sure Australians know the signs and symptoms and patients have access to the best treatments that are available in Australia.

For more information please visit our website:  
[www.lymphoma.org.au](http://www.lymphoma.org.au)



# LYNCH SYNDROME AUSTRALIA (LSA)



## KEY PERSONNEL:

Beth Fairbank, Founder-Managing Director, Previvor

Susan Watkins Morris, LSA Media Contact and Spokesperson, Director, Survivor

Toni Rice, Director, Survivor

Lynch syndrome is an inherited condition that predisposes the gene carrier to multiple, aggressive primary cancers at an early age. Lynch cancers can affect organs such as the colon, ovary, endometrium, stomach, hepatobiliary tract, urinary tract to name a few. Carriers have a 50% chance of passing the gene onto their children. Early diagnosis and vigilant surveillance are essential.

Lynch Syndrome Australia (LSA) is one of the country's newest charities and, as an all-volunteer survivor-led organisation, supports the many thousands of Australian families that carry the Lynch syndrome gene. LSA relies solely on donations.

## WE:

- Raise awareness of Lynch syndrome amongst high risk groups, the medical profession and the general public.
  - Encourage and empower people to take charge of their own surveillance and general health.
  - Support research into Lynch syndrome to improve surveillance and detection
- To date, we have held four Living with Lynch seminars and conducted awareness and information campaigns for health care professionals.

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Phone: 0420 294 191

Email: [info@lynchsyntax.org.au](mailto:info@lynchsyntax.org.au)

[www.lynchsyntax.org.au](http://www.lynchsyntax.org.au)

[www.facebook.com/LynchSyndromeAustralia](https://www.facebook.com/LynchSyndromeAustralia)

@LynchSyndromeAU





**VISION:** To reduce the impact of melanoma on all Australians

**MISSION:** Provide information, support, awareness and advocacy to people affected by melanoma; and, to become the national peak body representing the interests of melanoma patients in Australia.

Melanoma Patients Australia (MPA) was established in 2006 by patients for patients and is now the largest patient driven national organisation committed to the delivery of support, awareness, advocacy and information programs to reduce the impact of melanoma on all Australians. As the largest national independent, not for profit patient led organisation, MPA is dedicated to having a positive impact on the lives of melanoma patients across Australia.

MPA recognises the importance of our role as an independent and impartial organisation representing the needs and interests of melanoma patients in Australia. MPA works tirelessly to advocate on behalf of all melanoma patients in Australia regardless of geographical location; the patient's choice of treatment/trial participation; or the patient's treatment centre or institution.

The MPA support network is one of the largest in Australia and incorporates peer to peer support groups, a patient telephone line, online forum and social media. MPA employs a National Patient Navigator who is available to speak with melanoma patients from across Australia to assist them in engaging with relevant treating clinicians, research centres, and support services. MPA is committed to achieving the best outcomes for patients and we work directly with patients dealing with issues from diagnosis, treatment options, ongoing management and survivorship issues.

The Danger Sun Overhead program is run exclusively through MPA and promotes melanoma and skin cancer prevention, awareness, early detection and diagnosis to industry, sporting associations and educational organisations (schools etc). The DSO program is the leading not for profit service assisting industry comply with their OH&S obligations in relation to sun safety and skin cancer prevention.

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Web: [www.melanomapatients.org.au](http://www.melanomapatients.org.au)





**Myeloma Foundation  
of Australia Inc.**

***“A SMALL ORGANISATION DOING BIG THINGS FOR PEOPLE  
LIVING WITH MYELOMA”***

Myeloma Australia is dedicated to providing support, education, information, advocacy and research to help those affected by multiple myeloma.

The Foundation began in 1997, initiated by the carers of myeloma patients to enable services, information and access to medication and a better understanding of the disease. It was an entirely volunteer run organisation for many years.

The Foundation now employs two full time staff which includes the CEO, and an admin-fundraising-marketing officer, a part time finance officer, a research nurse and two support nurses. The Foundation receives no government funding and relies on the support and generosity of the community and philanthropic sector to further their work in assisting people affected by myeloma.

Myeloma Australia is the Trading name of Myeloma Foundation of Australia Inc.

CEO:	Steve Roach
Nurse:	Services and Programs Manager: Hayley King
Address:	335 Swan Street Richmond, Vic, 3121
Tel:	Ph: (03) 9428 7444 Toll Free: 1300 632 100
Email:	admin@myeloma.org.au
Web:	www.myeloma.org.au
Support Line:	1800 MYELOMA (1800 693 566)



# MARK GRUNDY OESOPHAGEAL CANCER AWARENESS GROUP INCORPORATED (OCAGI)



## **“DON'T BE AFRAID TO ASK!”**

When first diagnosed with oesophageal cancer, Polly Grundy's husband Mark soon found that there were no support groups, either on or offline, for his particular type of cancer within Australia. There was little information, and what was available proved hard to find.

OCAGI is dedicated to raising awareness of oesophageal cancer and to spreading our slogan throughout Australia. “Don't be afraid to ask.” We want to educate people to not just repeatedly visit their GP seeking remedies for heartburn and indigestion, but to:

Ask for tests. Ask to be referred to a specialist. Ask for advice on preventative lifelong health initiatives to change diet and lifestyle.

Through the OCAGI website we will provide a “hub” to access information from reputable organisations associated with cancer, cancer research and palliative care. We hope this site will give patients, their carers', family and friends, a place to source information, access resources, share stories and offer online support.

Through donations and fundraising events, OCAGI will provide funds for Australian research into Oesophageal Cancer - including its cause, prevention, treatment and care.

Mark Grundy Oesophageal Cancer Awareness Group Incorporated's (OCAGI) strives to:

- Provide a support network through meetings, online forums and communication within OCAGI website for oesophageal cancer sufferers, their caregiver/s and family.
- Raise awareness of oesophageal cancer to the wider community through the media, internet, OCAGI website and social media.
- Conduct oesophageal cancer awareness seminars for community groups, service clubs and business groups.
- Raise money through fund raising events, donations and grants to support Oesophageal Cancer research, to provide awareness seminars and training for carers and OCAGI facilitators.
- Provide funding and support for targeted oesophageal cancer research through the Ingham Institute and the Upper GI Viral oncology group
- Identify, develop and promote ways to educate people about making health decisions to change their diet and lifestyle to reduce their risks of Oesophageal Cancer

Address: PO Box 166 Ingleburn NSW 1890  
Email: [mgocagi@gmail.com](mailto:mgocagi@gmail.com) Facebook:  
Web: [www.facebook.com/MarkGrundyoesophagealcancerawarenessgroupinc](http://www.facebook.com/MarkGrundyoesophagealcancerawarenessgroupinc)

FOUNDER and PRESIDENT: Polly Grundy Ph: 02 9829 3999 Mob: 0468 794 664

OCAGI is run by volunteers and funded solely by donations and fundraising events.





## Ovarian Cancer Australia

[www.ovariancancer.net.au](http://www.ovariancancer.net.au)

Ovarian Cancer Australia is the national peak body for this devastating disease. Four women are diagnosed every day and unfortunately three will die. The five year survival rate is only 43% and there has been little advance in treatments for 20 years. There is no early detection test and not likely to be one in the near future because of the nature of the disease. It is vital that women are aware of the symptoms of the disease as sadly they can often be diagnosed at a late stage when there is less hope of successful treatment.

We work to provide support to women who are newly diagnosed and undergoing treatment; we raise awareness of the symptoms; we advocate on behalf of women with the disease and we fund and stimulate the research effort. Each year in February we hold Ovarian Cancer Awareness Month and one of our main fundraising activities the Afternoon Teal campaign.

### How consumers are involved in our organisation

We are committed to ensuring that the voices of the women from our community are central to our organisation. We have a consumer survey group that informs our advocacy work, and service development and delivery. We consult with consumers on the development of our key policies such as the National Action Plan for ovarian cancer research. We hold regular support groups both by phone and in face to face meetings. We hold seminars and symposiums which enable women and their families to understand research directions and treatment options. We have Ambassadors who are women with ovarian cancer, or their loved ones who work with us throughout Australia to raise awareness and to inform our work.

### A water shed moment for ovarian cancer in Australia

We have developed a national strategy for research - the National Action Plan for ovarian cancer research, which has been developed with wide consultation with the field. The report sets out where the best research is taking place and outlines the priorities for funding. We believe this will be a watershed moment in terms of pushing forward the research effort.

### **FUNDING**

As a grass roots organisation Ovarian Cancer Australia is funded by donations and fundraising from our community, as well as corporate sponsorship. At present we don't receive any recurrent government funding to provide the services to the women we support around the country.

Queen Victoria Women's Centre, 210 Lonsdale Street, Melbourne 3000

Phone: 1300 660 334

Patron: Nicole Livingstone

Chair: Paula Benson

CEO: Alison Amos, [Alison.amos@ovariancancer.net.au](mailto:Alison.amos@ovariancancer.net.au)

Research and Advocacy Manager: Katherine Nielsen, [Katherine.nielsen@ovariancancer.net.au](mailto:Katherine.nielsen@ovariancancer.net.au)

Support Services Manager: Julie Hassard, [Julie.hassard@ovariancancer.net.au](mailto:Julie.hassard@ovariancancer.net.au)

Communications and Fundraising Manager: Amanda Purdie, [Amanda.purdie@ovariancancer.net.au](mailto:Amanda.purdie@ovariancancer.net.au)





Prostate Cancer Foundation of Australia (PCFA) is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

### **WE DO THIS BY:**

Promoting and funding world leading, innovative research into prostate cancer

Implementing awareness campaigns and education programs for the Australian Community, health professionals and Government

Supporting men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses

PCFA receives Government funding for specific projects and relies on the generosity of individuals, the community and partnerships, such as those with the Movember Foundation and Commonwealth Bank, to carry out our essential work.

### **KEY PERSONNEL AND CONTACT DETAILS**

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Marie-Claire Cheron-Sauer  
Director, Support Network  
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St Leonards NSW 1595  
Ph: 02 9438 7022

Website: [www.pcfa.org.au](http://www.pcfa.org.au)  
Twitter: <https://twitter.com/PCFA>  
Facebook: <https://www.facebook.com/pcfa1>





Rare Cancers Australia (RCA) was formed in 2012 in response to the need of Australians with rare and less common cancers to have an organisation providing advocacy and support. RCA is based in Bowral, New South Wales and its key areas of operation as follows:

RCA works actively to contribute policy discussion and debate around cancer. The organisation is focussed on ensuring that at all times the needs and rights of those Australians whose disease places them outside the mainstream, are considered and catered for by the health system.

RCA aims to provide tangible assistance to individuals coping with cancer. The RCA website provides information on a range of rare cancers and RCA also provides financial assistance to those in need. RCA is launching a new initiative, The Cancer Medicines Fund, which aims to help fund life extending or lifesaving medicines where those medicines are not government funded through the PBS.

The third area of activity for RCA is promoting and fundraising for research into rare and less common cancers. RCA works closely with leading Australian cancer research institutes.

RCA was founded by Kate and Richard Vines and they remain its primary funding source. RCA has also received public donations, corporate sponsorship, pharmaceutical industry grants and grants from state and federal government.

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PO Box 440 Bowral, NSW, 2576

Phone: 02 4862 2768

Fax: 02 4862 2768

Contact: Richard Vines

Mob: 0409 660 003

Email: [richard@rarecancers.org.au](mailto:richard@rarecancers.org.au)

Web: [www.rarecancers.org.au](http://www.rarecancers.org.au)





# Unicorn Foundation

*Seeking the cure for  
Neuroendocrine Cancers*

The Unicorn Foundation is Australia's only not for profit medical charity directed to the needs of sufferers of neuroendocrine (NETs) cancers. The mission of the Unicorn Foundation is to assist and support patients and carers through support groups and access to networks of expertise; to lobby for access to new and appropriate investigations and treatments; to raise awareness about NET cancers within the medical community and general public and to encourage and support Australian research in the area of NET cancers.

Considered to be a less common cancer, rates of neuroendocrine cancers have doubled over the last decade and they are now the second most common gastrointestinal malignancy after colorectal cancer. This increasing trend is expected to continue.

The Unicorn Foundation raises awareness and education of NETs, and provides Australia-wide patient support through organized group meetings and a telephone/ internet NET Nurse Specialist 'help-line'. Importantly, we fund Australian based research in all aspects of the disease – diagnosis, management and treatment, hoping one day that we will find a cure. All of our activities are funded solely on our fundraising efforts and receive no government funding.

## Contact Details:

Simone Leyden CEO

Dr John Leyden Chairman

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Email: [sleyden@unicornfoundation.org.au](mailto:sleyden@unicornfoundation.org.au)

Website: [www.unicornfoundation.org.au](http://www.unicornfoundation.org.au)

Twitter: [@unicornfound](https://twitter.com/@unicornfound)

Facebook: [www.facebook.com/unicornfoundation](http://www.facebook.com/unicornfoundation)



# THE WALDENSTRÖM'S MACROGLOBULINEMIA COMMUNITY IN AUSTRALIA



Waldenström's Macroglobulinemia (WM) is a rare blood cancer, incurable with current medical science. In normal course, WM is an indolent lymphoma and requires ongoing case management with thoughtful monitoring by patient and physician.

Practical support, advocacy, discussion forums and information - for patients and carers

WMozzies is the Australian patient support group of the International Waldenström's Macroglobulinemia Foundation (IWMF). <http://www.iwmf.com/>

IWMF provides a wealth of information and patient support services internationally. It also funds a major research effort towards finding a cure for WM.

The Leukaemia Foundation in Australia is affiliated with WMozzies.

For WMozzies their highly trained support services team provides emotional support, information, education programs, accommodation, transport, advocacy and practical assistance.

## Contact Details:

Tracey Dryden

Tel: 03 9949 5823

Email: [lymphoma@leukaemia.org.au](mailto:lymphoma@leukaemia.org.au)

Website: <http://www.wmozzies.com/home>

WMozzies has a national advisory group of 4 WM patients.

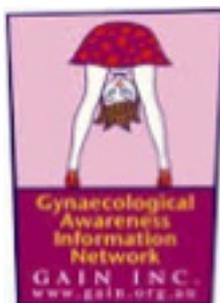
Group leader is Andrew Warden 0408 303 718 [andrew.warden@bigpond.com](mailto:andrew.warden@bigpond.com)

# WITH THANKS TO OUR NETWORK



**BREAST CANCER  
ACTION GROUP NSW**







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