



Cancer Voices Australia is a national consumer organisation representing Australians affected by cancer.

We aim to ensure the voices of people affected by all the different types of cancer are heard at a national level.

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PATIENTS CONCERNED MORE ABOUT PATS THAN THEIR HEALTH

Patient Assisted Travel Schemes (PATS – known by a different name in some states) provide financial assistance for rural patients needing treatment in regional and metropolitan 'cancer centres'.

Cancer Voices Australia, and its representative organisations in each state believes that the government must address this matter urgently. A recent report commissioned by the Cancer Council NSW stated – "Patients were more concerned about PATS than their health"

This statement alone should make governments question what they are doing!

There is not much that a cancer patient can do when diagnosed. They are referred to the appropriate treatment centre/clinician, but getting to the nominated place of treatment, directly involves them, their family and their carers.

PATS is the subject of a continual blame game between Federal and State Governments – to the detriment of many patients. PATS was recently the subject of a focussed report by the Senate Community Affairs Committee. This report recommended a plan of action leading up to the forthcoming COAG meeting which will consider the next five year health plan.

Major failings of the current system are:

1. No provision in any Health legislation to provide PATS which could be achieved through a national framework
2. An urgent need for regular reviews of reimbursement rates against real costs including CPI adjustments
3. PATS must offer the same type and level of reimbursement to patients on clinical trials
4. The evidence of poorer survival of cancer patients from rural areas due to lack of access to travel and accommodation support, highlights the need for an increased PATS scheme

CVA through its state organisations has collected a cache of stories –

some are outlined below:

- The process can be so stressful and difficult for patients and their carers, that many people decide not to have treatment at all. (WA, SA NSW, VIC)
- The scheme won't fund over 6 months which adversely affects haematology patients whose treatment often extends for over 6 month (All states)
- There is no meaningful increase in the rate of reimbursement - and certainly not in line with inflation or the recent increase in fuel prices. (All states)
- Many people live just under the designated km limit, e.g.: limit is 100 kms and a person living 95kms from the treatment centre has no flexibility at all - those people have to absorb the complete cost of travel. Victoria does have a sensible gap protection (75 – 99kms) (WA, NSW, SA)
- One patient lives 10kms from the centre of town, but the GPO address is 97kms so there is no eligibility under the current strict guidelines. (WA)
- The scheme requires up front payment - many cannot afford this
- Social workers spend many hours advocating with PATS personnel, accommodation providers, and chasing Drs to fill forms, etc. (NSW, SA, WA)
- In QLD, - individual hospitals administer the scheme
- Many people, including locum doctors, still don't know about the scheme. (All states)
- Consistent reports of PATS staff not being helpful or inconsistent (NSW, WA, SA, VIC)
- Charities fill the gaps. (All states)

CVA has highlighted the above with the Federal Health Minister and the Rural Health Division of her Department. We await a response.

FROM THE CHAIR

Consumers in Research

In March about 250 researchers and consumers attended a forum in Perth about Involving People in Research. The forum issued a communiqué calling on the National Health and Medical Research Commission (NHMRC) to form a national body to advance more effective participation of consumers in research activities. A number of organisations, including CVA, met the NHMRC Advisory Council in late August. It remains to be seen whether further support is forthcoming from NHMRC for consumer involvement.

Meanwhile, the Australasian Gastro-Intestinal Trial Group (AGITG) formed a Consumer Advisory Panel of 11 gastro-intestinal survivors with me as interim chair. In August I participated in a small gathering of clinicians who devised a trial of a new treatment protocol for colon cancer which has metastasised to the liver. This proposal was reviewed by the full consumer panel later in August. Finally I represented the collective consumer position to the AGITG Scientific Advisory Committee in early September. It was decided that the proposal should be put forward for funding as an AGITG sponsored clinical trial.

When the trial is funded – possibly from early 2010 onwards – there will be a continuing consumer panel involvement through to completion some 5-7 years later. So far, this pilot is confirming that consumer involvement in developing research works.

There are requests for consumer involvement with 8 other research organisations covering about 40 research/trial projects. These requests reinforce the message that more consumer training is required. In early September Cancer Council NSW conducted a consumer-in-research training course in Sydney. Among the 40 or so consumers who attended, were 8 from the AGITG panel and another 12 consumers recently recruited by Cancer Australia to become involved in its grant proposal assessment.

Health Reform

The National Health and Hospitals Reform Commission (NHHRC) finish its public hearings soon and will make a preliminary report to the government's meeting in October. In late August NHHRC held a meeting with major disease groups, focussing on a means of implementing the many disease strategies and specialist reports which have been in limbo, in some cases, for many years. Cancer Council Australia and CVA were among the dozen or so organisations present. The hearing provided an opportunity for organisations present to stress the importance to chronic illness patients of, among others, Patient Assisted Travel schemes and the introduction of Electronic Health records (e-Health).

Bowel Screening

In the May budget the Federal Government extended Bowel Cancer Screening to people turning 50. While this is welcome, there is no good evidential reason for limiting screening to people as they turn 50, 55 and 65. We look forward to bowel screening becoming available to all people over 45 on a biennial basis, as happens in most other countries where bowel screening exists.

We also share the widespread concern about the relatively small number of people who are taking up the current cancer screening opportunities. I have been invited to join a working group, led by The Cancer Council Australia, to devise a national communications strategy for the screening program. CVA also attended a recent forum sponsored by Roche to set up a collaboration of concerned organisations to advance community awareness of bowel cancers.

CVA has raised our concerns with the Federal Health Minister and we await her response.

John Newsom

E-HEALTH

CVA welcomes the National e-Health Transition Authority's engagement in an inclusive cross community consultative process at all stages of its development and implementation. For cancer consumers, this is most welcome.

E-health is a complex issue which requires whole of community participation to achieve its ultimate goals. CVA believes that successful implementation must have a quality governance structure to maximise the inclusion of all relevant community interests. This structure will need to incorporate a management team which includes all parties and a structure to incorporate the knowledge, skills and needs of its constituents.

It is essential that all concerns and view points are handled such that they can be fully understood and properly dealt with. A totally inclusive examination and broad agreement will make a significant contribution to cancer patients' needs.

In short, the need is to create a continuum of teamwork to establish a quality system for e-Health data linkage.

The principles involved in setting up a body to tackle such challenging collaborative tasks are not new. There are successful models which can be a basis for close consideration in determining the best option.

The point at this time is to recognise that successful inclusive community-wide governance must be the priority and is itself the prime challenge for the implementation of the concept of whole of community teamwork.

CVA will continue to work with NeTHA to ensure the needs of cancer consumers are heard and included.

INTERNATIONAL UNION AGAINST CANCER (UICC)

As an associate member organisation, CVA was represented at the World Cancer Congress organised by the UICC at Geneva in August 2008. John Stubbs and Leonie Young (CVQLD) attended, along with Denis Strangman (CVACT) in his role as Chair of the International Brain Foundation. Over 2500 delegates attended and it was a wonderful opportunity to meet with many of the European and UK cancer coalitions. They were impressed with the dynamic role consumers in Australia play in addressing issues with their respective governments.

The World Cancer Declaration 2008 is a tool to help cancer advocates bring the growing cancer crisis to the attention of health policymakers at national, regional and global levels. It represents a consensus between foundations, national and international non-governmental and governmental organisations, professional bodies, the private sector, academia and civil society from all continents that are committed to the vision of eliminating cancer as a major threat for future generations.

The UICC has asked its member organisations to endorse the world Cancer Declaration and this was a highlight of the conference with a number of emotive speeches from country leaders. The endorsement is designed to communicate with world leaders that the global cancer community stands united behind this call for action to reduce the cancer burden significantly by 2020.

Australia is now in a most responsible position to be a leader in this declaration as the CEO of the Cancer Council Victoria Professor David Hill AM was appointed Chair of UICC for the next two years. We congratulate him on this international recognition.

PHARMACEUTICAL BENEFITS' ADVISORY COMMITTEE (PBAC)

The recent announcement by the Minister for Health and Ageing Nicola Roxon to allow cancer consumers to comment on medicines being considered for listing on the Pharmaceutical Benefits Scheme (PBS) is well received.

The Pharmaceutical Benefits Advisory Committee (PBAC) makes final decisions about which medicines are listed on the PBS. A consumer representative is a member of the Committee, but this initiative allows more direct consumer input into the decision-making process.

Cancer patients will now have a better understanding of the process and CVA commends the efforts of cancer patients, advocacy groups and cancer organisations who have engaged with the Government and the Public Benefits Advisory Committee to achieve this policy change.

The PBAC meeting agenda is now publicly available on its website six weeks before each meeting, stating which medicines are being considered. Cancer patients will have access to an online form for the following two weeks to comment on how they, their family and carers would benefit from PBS listing of a particular drug. Comments will be examined by the PBAC and the pharmaceutical company that is seeking PBS listing prior to the meeting.

For a cancer patient to have access to the drug listing process and be able to provide their 'patient impact statement' opens a new chapter in Government - consumer relations. Future cancer patients will benefit from this decision at a time when it is most needed.

CANCER AUSTRALIA (CA)

CVA continues to work closely with Cancer Australia and currently has 8 representatives on national committees. The Chair of CVA recently met with Professor David Currow CEO Cancer Australia. One issue raised was the appointment of the new Chair of the National Consumer Advisory Group and offered some suggestions in this regard.

The CanNET projects in all states are gaining momentum and the general consensus from state CV's is for more consumer engagement. This has started to occur as more and more project officers understand the benefit of consumer input from the outset.

AUSTRALIAN BLOOD CANCER REGISTRY (ABCR)

Blood cancers such as lymphoma, leukaemia and myeloma are a significant health concern in Australia. They account for 10% of all cancers with non-Hodgkin lymphoma being the fifth most common cancer.

Prior to the development of the ABCR, state registries collecting data on blood cancers did not have a central repository to - consolidate valuable information gathered. ABCR's establishment has made inroads with projects such as implementing and piloting data collection, communicating the development of the ABCR with key stakeholders and garnering clinical and financial support.

The ABCR is collecting detailed and accurate information on blood cancers. This information will be used to improve the capacity of clinicians, patients, their families, carers and governments to make informed and timely decisions on the management of blood cancers.

The ABCR will provide clinical haematologists and oncologists with accurate and detailed information to improve survival and treatment outcomes and set standards to achieve best practise in clinical care.

The Leukaemia Foundation provides its services as Secretariat for the ABCR. Find out more about the ABCR at www.abcr.net.au.

PHARMACEUTICAL INDUSTRY ASSOCIATION

For CVA's recently released Policy on Dealing with Pharmaceutical Companies, please go to our website at www.cancervoicesaustralia.org.au

NATIONAL INSTITUTE OF COMPLEMENTARY MEDICINES (NICM)

CVA, along with other interested organisations attended a meeting organised by the institute. NICM was established mid 2007 to provide a coordinated and national approach to building research capacity and addressing complex issues around complementary medicines (CM), e.g. the role of CM in the health system and establishing reliable and accurate information about safety, efficacy and value. NICM is currently preparing a 4-5yr funding proposal for submission to the Government. The plan is to develop a website providing reliable and accurate information about CM (safety, efficacy and value) for consumers and health professionals.

The following issues were discussed:

- Consumers need awareness of potential risk of CMs, particularly if self-medicating
- Consumers cannot assume CM is safe
- Consumer uses include spectrum of care from maintenance of wellbeing to illness prevention and treatment
- Consumers not using 'evidence' to make decisions about CM use

- Consumers need to be trained to read labels and identify active ingredients in order to compare dose and price.

There was strong emphasis on using 'cancer' as a focus to narrow the scope, provide a template for establishing an information resource format (details/ items to include and layout) and 'riding' with the interest of cancer groups to support this development.

This work would identify (and link to) existing information resources as well as highlighting areas where more research or synthesis of evidence is needed. Additional information would include tips on how to identify accredited CM practitioners. The need for consumer involvement was firmly stated.

The meeting heard of the Cancer/CMs resource soon to be released by Cancer Council NSW. Professor Ian Olver CEO Cancer Council Australia has reviewed the resource and describes it as one of best resources he's seen, including conventional and experiential evidence guiding CM use.

CVA will continue to work with the NICM on this important issue.

IN YOUR STATE

Cancer Voices VIC (CVVIC)

CVVic was recently invited by the Victorian Government as an advocacy organisation to comment on Victoria's Cancer Action Plan 2008- 2011. The aim of the action plan is to invest in innovative prevention, treatment and research activities. CVVic is part of a small select group of cancer care leaders to discuss the action area of the plan and develop proposed priorities and targets.

Ian Roos (Former CVVic Chair) has also been very involved with the "chemotherapy companion" produced by Hume Region Integrated Cancer Services Area.

A training program took place recently for CVVic's new volunteers. The government has also included CVVic as part of a training program for CanNet scheduled to commence shortly.

CVVic is looking to replicate a similar training program for Consumers in Research to that recently attended by its members in Sydney.
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Cancer Voices SA (CVSA)

The announcement that Lance Armstrong is coming to Adelaide in January to participate in the Tour-Down-Under and raise cancer awareness is a very exciting opportunity for all Cancer Voices.

CVSA has been prominent in the media spotlight during recent months, advocating for the 869 radiotherapy patients whose cancer treatment may have been compromised because of a calibration error that went undetected for 2 years.

In July 2008 it was revealed that 760 patients, treated between mid 2004 – and mid 2006 were to be invited for clinical review because they received a 5% reduction in prescribed radiotherapy dose when treated on one of the four Linear Accelerator machines at the Royal Adelaide Hospital. Two weeks later a further 114 patients were notified that they too had received radiotherapy on the machine in question.

CVSA was the lone voice speaking out on behalf of patients, and moved quickly, meeting with the Chief Executive of the SA Department of Health to raise concerns, and provide input to the Independent Inquiry, and presenting a consumer perspective in the media (newspapers, television and radio).

CVSA voiced concerns that systems be reviewed and:

- procedures put in place in all public and private radiotherapy facilities to ensure errors are prevented or quickly picked up (i.e. cannot go unnoticed for 2 years)
- the poor communication of this issue with patients be evaluated
- data quality issues be addressed (e.g. missing details in patient records impeded rapid identification of patients impacted by this calibration error)
- questions asked about why independent calibration checks through Dosimetry Standards are not in place. (N.B. CVA has supported us with action at the national level).

Work on this issue continues through the Cancer Clinical Network and Safety and Quality Committees to implement the 14 recommendations of the Independent Inquiry and broader CVSA concerns (outside the Inquiry scope).

Meanwhile, cancer consumer representation on various Statewide Cancer Clinical Network committees report continued good progress, and a new subgroup – the Complementary Therapies Working Party is being chaired by Ashleigh Moore, Chair of CVSA Executive.

A 'Planning Day' for the CVSA Executive was held in August with Sally Crossing from CVNSW providing helpful background, insights and advice around issues such as sustainability, policies, operations, and communication.

A new member of the CVSA Exec, Louise Murada, brings expertise and vigor with her focus on survivorship issues for children, adolescents and young adults with cancer.

So in SA, there is much to do, and much 'riding on' consolidation of our efforts in cancer advocacy, awareness, involvement and information.

Ashleigh Moore - Chair

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Cancer Voices TAS (CVTAS)

The last few months have involved issues associated with the state Department of Health's enquiry into PTAS (PATs). As with other states, this matter continues to be of major concern to cancer patients and their families.

There has also been a public controversy regarding the provision of a licence for a PET scanner for the state which members have long advocated for. At this stage the PET machine is not operational but CVTas is confident that all patients state-wide will soon have access to PET scanning.

An ongoing issue for women across the state is the lack of a public diagnostic mammography screening service. Members of CVTas are involved in continual advocacy and discussion with the Government to provide this service.

It was a commitment of the Labor Party in the last State election campaign - a commitment which is yet to be fulfilled!

A recent membership drive has boosted our numbers and we are hopeful that public forums across the state in November as part of Cancer Australia's CanNet Tasmania's consumer consultation will further enhance interest in Cancer Voices Tasmania.

Karen Forster - Chair

Cancer Voices NSW (CVN)

Cancer Voices NSW has had a busy quarter – see Newsletter no. 32, available on the website www.cancervoices.org.au.

As the “older sibling” celebrating our eighth year, CVN may be able to assist newer Cancer Voices. Cancer Voices WA, later Cancer Voices VIC and most recently, Cancer Voices SA, have invited CVN to talk about establishment – lessons learned and insights gained. It is an ongoing process, but CVN is keen to share its knowledge and expertise.

The main issues for CVN this year are:

- Access to radiotherapy services
- Supply of medical oncologists (NSW is missing 56!)
- Access to palliative care
- Access to multidisciplinary care teams
- Cancer services provider directories
- A Treatment & Care Plan for cancer patients
- Speeding access to personalised cancer treatment
- PET Scans for all cancers, where evidence recommends
- Superannuation without penalty tax for the younger & sicker (Stage 2)

These are gathered from our Area Cancer Service Representatives and from members' feedback. The Cancer Council NSW provides several pro bono services to CVN – one is the underwriting of the six-weekly ACS Representatives teleconferences. Others are the printing and mailing of our newsletters and making relevant conference attendance possible. This works well.

The Cancer Council NSW is keen to share the Consumer Advocacy Training course developed in partnership with us in 2002, and fine-tuned over the years.

CVN asks that all reps be graduates of this, and/or the Consumer Research Training course. For further information see our website.

CVN currently has 48 reps sitting on 113 committees, mostly at state level. Please see our website for Consumer Representation Forms – these are for organisations looking for a CVN nominee.

CVN continues to develop Position Statements (see website). They may be of use to other organisations as they develop their own. CVN looks forward to working with CVA towards producing common CV statements on the bigger issues for most impact.

A new NSW Minister for Cancer has been announced, Tony Stewart, replacing Verity Firth. Minister Firth was a pleasure to work with.

CVN is co-hosting (with CCNSW) the COSA Consumer Forum on 17 November, “Nothing about us without us” and hope we will see some of you in Sydney then.

Sally Crossing AM - Chair

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Cancer Voices QLD (CVQ)

The inaugural CVQ Annual General Meeting was held in August, a significant milestone in the development of this organisation in Queensland.

CVQ continues to raise community awareness through two Public Forums, one in Emerald in central Queensland and the other at Maroochydore on the Sunshine Coast. These public forums provide the opportunity to identify issues both positive and negative about the Queensland health care system that need to be addressed and thus assist CVQ to be truly a voice for all Queenslanders affected by cancer.

In October, ten members will attend the annual Advocacy Training workshop which is a joint collaboration between CVQ and the Cancer Council Queensland. These workshops seek to provide skills and knowledge to members to assist them to be more effective consumer advocates in the community.

They particularly concentrate on communication skills and understanding true advocacy.

CVQ has plans to broaden the support provided to its members who have already undertaken training, by offering an annual refresher workshop more specifically related to consumer representation on committees.

Leonie Young - Chair

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Cancer Voices ACT (CVACT)

Cancer Voices ACT met with CVA Chair John Newsom and CVA EO John Stubbs during their recent visit to Canberra and CVA Board member Denis Strangman (ACT) accompanied the two on their visits to key contacts in the ACT.

A CVACT member attended the recent Chronic Health Forum. With a Territory election due on 18 October, cancer has not yet featured as an election discussion subject but there are a number of issues needing attention:

- Canberra and district residents are still being sent interstate for radiation therapy despite the opening of a new Linac machine
- The question of hospital payment for non-PBS oncology drugs has also been discussed at meetings of the management committee of the Capital Region Cancer Services

CVACT Chair Denis Strangman, who also chairs the International Brain Tumour Alliance attended the recent World Cancer Congress in Geneva. IBTA was disappointed that the UICC's World Cancer Declaration did not contain mention of the special needs of the less common and/or intractable cancers, of which brain tumours and pancreatic cancer are two examples.

Denis Strangman - Chair

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Cancer Voices WA (CVWA)

Following the recent election, WA has a new state government.

This will now have a significant impact on the current development of new cancer services most of which will not come on stream until 2013 onwards. A recent Cancer Council report- the 'Barton Report' looks at the capacity of the existing services to provide adequate treatment and support for patients until new services are fully developed. The report was launched on August 20th and featured as the lead story on the front page of the West Australian. The report confirmed many of the issues that CVWA and individual patients have raised over the last 18 months. Our Director General for Health is also in an acting capacity as the outcome of the interview process for the permanent appointment was frozen as a consequence of the election.

Meanwhile CVWA's current list of issues continues to feature radiotherapy waiting lists; access to new technology; MRI waiting lists and PATs. Add to that the topic of whether or not medical oncology departments in public hospitals will allow patients to purchase their own drugs if the hospital does not provide them (in addition whether their medical oncologist will then administer them).

On access to technology and after a year of lobbying, WA will have two IMRT units (Intensity Modulated Radiotherapy) at the beginning of next year; one public and one private. This will mean patients requiring treatment will not have to travel to other states and spend weeks away.

Clive Deverall – Chair

www.cancerwa.asn.au/patients/cancervoices

NATIONAL AGENDA

During the period under review, CVA has attended, provided keynote addresses, spoken at two international conferences, 18 seminars, six board meetings, and attended 14 government committees.

CVA consumer representatives continue to provide policy and advice and promote the value of consumers to governments and interested parties.

MEETINGS

- Cancer Australia -CanNET NSW and National Project (monthly)
- Selection Committee for Applications for Consumers in Research Project
- APUG - Board of Management (monthly)
- Board Meetings - Cancer Institute NSW, COSA Council, Cancer Council Australia
- Bowel Cancer Consortium – Forum and Meetings x 2
- Australian Blood Cancer Registry (monthly)
- Australian Leukaemia Lymphoma Group (quarterly)
- NHMRC – Consumers in Research
- NHMRC – Observers Grants Process
- NHHRC – Submission and Meeting www.nhhrc.org.au

CONFERENCES/SEMINARS

- APUG – Christchurch - August
- E-Health - Canberra - July
- Australian Institute of Health Policy Studies Brisbane – Facilitator
- UICC – Geneva
- AGITG – Annual Scientific Meeting, Sydney - September
- Brain Foundation - Annual Research Awards

POSTSCRIPT

CVA is saddened by the recent voluntary winding up of Brain Tumour Australia. CVA has maintained a close relationship with this organisation and provided initial advice to the group in its infancy. CVA EO John Stubbs provided valuable and insightful feedback at the inaugural meeting where more than 100 attendees joined together to form the Consumer organisation.

BTA's success to date had been driven by the deep commitment of a small dedicated group of people. Credibility has been established with health professionals in the wider brain tumour community and the overwhelming need for a health professional/consumer partnership to further the needs of brain tumour patients and their families has been identified.

FOR YOUR CALENDAR

- Carer's Week
20 October 2008-09-30
www.carersaustralia.com.au
- International Brain Tumour Alliance Awareness Week
26 October 2008
www.theibta.org
- Pink Ribbon Day
27th October 2008
www.pinkribbonday.com.au
- Prostate Cancer Foundation Australia National conference
16-17 November 2008
Gold Coast Queensland
www.prostate.org.au
- Clinical Oncological Society Australia ASM
Sydney Convention Centre
18-20 November 2008
www.cosa.org.au/ASMEvents
- Medicines Australia/DoHA Joint Medicines Policy Conference
Hotel Realm, Canberra
25-26 November 2008
www.medicinesaustralia.com.au

GET INVOLVED WITH CVA

CVA seeks consumer involvement from interested persons.

Please visit our website at:
www.cancervoicesaustralia.org.au/involved.htm

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CVA also appreciates the generous input from cancer consumers who want to make a difference.

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