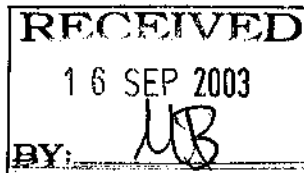


Ms Jane Schwager
Chair, Charities Definition Working Group
The Board of Taxation
C/- The Treasury
Langton Crescent
Parkes ACT 2600

P29

Cancer
VOICES
NSW



Dear Ms Schwager

Consultation on the Definition of a Charity

Cancer Voices NSW wishes to provide a submission to the Board of Taxation's Consultation on the Definition of a Charity. We have examined the helpful documents on your website as well as the Charities Bill 2003.

Cancer Voices NSW, the voice of people affected by cancer in our state, is a coalition of 80 cancer support and advocacy groups. We directly represent around 4,000 people who are living with or have experienced cancer, and work to promote the interests of the 29,000 who are diagnosed with our disease each year in NSW. Our "truly altruistic" objective is to reduce the impact of cancer on the community, in terms of lives affected and lives lost. All our work is done on a voluntary basis, relying on donations and without government or health sector funding to maintain our independence.

We support the position put forward in the submission of the Breast Cancer Action Group NSW (combined with BCA VIC). BCAG NSW is a founding member group of Cancer Voices NSW. As our role and objectives are very similar, our concerns about the definition of a charity within the Charities Bill 2003 are identical. Like the former, we are concerned that the admirable recommendations of the report from the *Inquiry* are not better reflected by the proposed Bill. We also believe that its "workability" will be difficult. Less clarity of definition and a greater administrative burden for charities looks very likely under the Bill's provisions.

While Cancer Voices NSW has not applied for Deductible Gift Recipient status to date, we wish to be able to do so in the future, without the uncertainties and ambiguities which the proposed process appears to perpetuate.

Perhaps a different approach for charities which are directly funded by government to those which are independently funded should be considered. We understand that while the Government is keen to encourage the community to look after its own, it is discomforted by what may appear to be, or indeed is, criticism of its policies by those charities receiving its direct support. Perhaps more rigorous accountability could be required where government funding is received to address that concern.

Helping people with cancer is the main objective of Cancer Voices NSW. The ways we do this vary and may include advocacy on behalf of the interests of those we work for. For instance, this year saw the successful culmination of our engagement with the NSW Government for a real focus on patients needs and outcomes in the delivery of cancer care our state. Together with a number of partners / stakeholders in the cancer sector, we participated in the development of the NSW Cancer Policy. This provides an extra \$294 million over the next four years. As

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representatives of "cancer people" we remain an integral part of the implementation of this policy and the direction in which the funds are expended. We do this because we can see that these initiatives will improve the journeys of people affected by our disease.

Like many other government agencies, the Health Insurance Commission explicitly states "The participation by consumers is increasingly recognised and sought by governments as a way of improving the quality of care and making the system more accountable" (*HIC Consumer Information needs Review, 2002*)

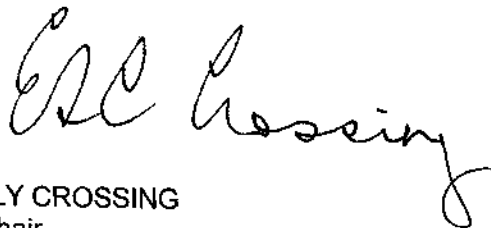
We believe that if "truly altruistic" consumer groups are invited and expected to participate in government health policy making by providing the consumer point of view - and they are -, then government should make some allowance via the tax system, in this case via DGR status, to assist them to do so. This would recognise the value they add to the process by offering the "essential perspective" of the people for whom the services are provided. DGR status is the most helpful form of tax system assistance for small charities like ours, which rely solely on donations.

In conclusion:

We suggest that the Taxation Board puts forward a recommendation that the Bill clarifies the criteria for eligible charities beyond doubt and beyond individual tax officers' interpretation. Criteria should acknowledge and include the very different types of charities that are working within the Australian community to improve the lives of our fellows afflicted by disease, and should not exclude the use of one of the many tools for achieving this, which is advocacy.

We attach the submission of the Breast Cancer Action Group NSW.

Yours sincerely



SALLY CROSSING
Co-chair

12 Sept 2003

CONSULTATION ON THE DEFINITION OF A CHARITY 2003

Submission by the BREAST CANCER ACTION GROUP(NSW & VIC)

This legislation is "intended to provide clarity to entities within the charitable sector." This is an important aim, which the Breast Cancer Action Group supports.

However, it is doubtful if this aim of providing clarity has been met. We are concerned with a number of aspects of the proposed legislation particularly:

- Disqualification of organisations involved in "attempting to change the law or government policy".
- Unworkability of the Bill through lack of clarity and therefore capacity for arbitrary and inconsistent application of the disqualifying purposes.
- Restricted scope of the legislation, particularly in that it does not address the definition of Public Benevolent Institution, or eligibility for Deductible Gift Recipient status, and therefore does not deal with the major complexities of tax definitions affecting the work of our organisation.

Constitution and purposes of BCAG

BCAG Victoria was formed in 1994 by women committed to reducing the impact of breast cancer in the Australian community, through advocacy, in terms of both lives affected and lives lost. BCAG NSW started in 1997 and there are now similar groups in all states and territories. All our work is undertaken by volunteers.

BCAG Victoria is incorporated under the *Associations Incorporation Act 1981 (Vic)*. BCAG NSW is incorporated under the *Associations Incorporations Act 1984 (NSW)*. Membership is free, and funding is received through donations from members and from grants. We have not been granted Deductible Gift Recipient status, and this is a major impediment to funding particularly through grants from charitable foundations, which require this status.

The objectives of both BCAGs are outlined in the constitutions as follows:

Objectives of the Breast Cancer Action Group

- To reduce the impact of breast cancer on the community, in terms of lives affected and lives lost
- To improve the experience of those undergoing treatment for breast cancer
- To encourage those with experience of breast cancer to contribute to all levels of decision-making about this disease
- To work towards ensuring access to the highest quality treatment services for people with breast cancer, regardless of their geographical location, social and or economic status or stage of disease
- To promote and contribute to research into the cause, prevention and optimal treatments of breast cancer
- To provide a forum for women and men to share their experiences of breast cancer.

BCAG Activities

Members of BCAG number approx 1400 women who have been affected by breast cancer in NSW and Victoria, about a third of whom live in the country. They receive an informative newsletter every quarter which discusses current issues, new research findings, personal experiences and provide information about creditable services that can help members and others like them. Members are also offered information sessions when speakers who are well known in their fields update them on identified topics of interest. These are opportunities for women with the same experience and urge to help others like themselves to meet and exchange information.

To keep abreast of the needs, problems and suggestions of women affected by breast cancer, we undertake regularly survey our members. The results of these surveys are used to focus the attention of cancer sector decision makers (eg *A Survey of Women's Experiences of Breast Cancer in NSW, Nov 2001 ISBN 186507 071 8*). We maintain websites so that people can find out about our work and contact us for information. BCAG NSW has produced a first-of-its-kind *Directory of Breast Cancer Treatment and Services for NSW Women*, which has been very well received by referring GPs and newly diagnosed women. Both BCAGs produce occasional informational leaflets about identified issues and distribute them widely.-

To enable our "voice" to be heard where decisions are made, we nominate trained and informed consumer representatives to take seats at decision-making tables. We engage in health sector and public discussion, provide media comment, present to seminars and conferences and contribute the informed patient view to national and international medical and scientific journals.

Thus the role of the Breast Cancer Action Group outlined in our constitutions and in our practical operations is both to provide services to women and to influence government / health sector policy. Indeed both roles are important. For example we offer services, particularly information, education and support to women to ensure that they are able to contribute to decision making about their own treatment and quality of life, and to help others to have better experiences.

Providing Advice

But at the same time, we are invited by governments, and other non-government organisations, to help determine policies and services. In relation to government invitations to participate, the Victorian and New South Wales governments have invited members of the Breast Cancer Action Group to sit on a number of major committees to help determine the delivery of cancer services in the states. This applies to both breast cancer and other cancers as appropriate.

At the national level, for example, BCAG representatives assist the National Health and Medical Research Council (through the Consumer Health Forum of Aust) to assist in developing documents which meet the needs of medical practitioners in Australia. Both BCAG Victoria and NSW provide representatives for Commonwealth government committees such as BreastScreen Australia National Advisory Committee and National Quality Management Committee. We are currently making an invited submission to the ALRC Inquiry into Gene Patenting and Human Health.

This advice helps ensure that the policies determined by government are as effective as possible. We work with governments, non-government organisations, clinicians and other medical staff in *partnership*. When we provide advice to governments, we wish to improve the delivery of services for the benefit of all women. We inform government thinking and we

seek to influence government. But this is *advice* to government, it remains up to governments to decide whether or not to accept the advice provided.

We see no problem, no conflict of interest with providing advice, suggesting changes, modifying service delivery and do this through representation on many different committees. Governments themselves obviously appreciate this advice. If they did not, invitations to participate on these committees would not be forthcoming. Government recognises that involvement of groups such as ours has become an integral and increasing part of government policy development; it ensures that its decisions take into account the input of those for whom they are being made.

Our view on "Disqualifying Purpose"

As outlined above a core part of the role of BCAG is providing advice to government, by and on behalf of women who have experienced breast cancer. This could arguably be seen as a disqualifying purpose in that this advice could seek "to change the law or government policy". Yet the government invites and welcomes this advice as a vital part of community consultation.

The proposed wording of the disqualifying purpose fails to recognise that seeking to change or influence government policy is a vital role for charitable organisations in a pluralistic society. Organisations like BCAG, whose members share the "essential perspective" of having experienced cancer, take on the responsibility of collating broad and considered views, and seek development of new policy approaches and enhancements of existing policy to meet newly recognised needs – which may not be recognised otherwise. Surely this activity should be supported and recognised.

It is worth noting that the *Report of the Inquiry into the Definition of Charities and Related Organisations* proposed a very different disqualification, namely: "Activities must not be illegal, contrary to public policy, or promote a political party or a candidate for public office." This wording would provide greater recognition that a charitable organisation could operate in accordance with broad public policy (which encourages consumer involvement in health) but at the same time seek to change policies and laws.

Workability of the disqualifying purpose

One of the main problems the BCAG has experienced is the lack of clarity involved in the discretionary application by Australian Taxation Office staff of the various relevant definitions.

We are well aware that other consumer groups with almost identical objectives to our own (eg the Breast Cancer Network Australia) have been granted DGR status, while we to date have not. There is patently a flaw of the present system which should be addressed by the Bill. But under the proposed new definition, ATO staff would again have discretionary power to determine whether a disqualifying activity was "more than ancillary or incidental to the other purposes of the entity concerned." This creates the same problem that we have had in the past: it is the tax office staff who decide whether or not the actions are incidental or ancillary. Thus the clarity that the charitable sector sought and the legislation aimed to provide has not been met.

Scope of the Legislation

BCAG is financially small organisation run entirely by volunteers. As such, many of the tax benefits provided by recognition as a charity are of limited relevance. However it would be of significant benefit for BCAG to be able to receive grants from charitable foundations. These grants are generally restricted to organisations that have deductible gift recipient status. BCAG NSW has been offered donations by private individuals and companies who value our work, but usually on the condition that donations are tax deductible.

For BCAG, the complexity of the tax system and the problems with the lack of clarity of tax definitions are related to Public Benevolent Institution and Deductible Gift Recipient status rather than just the definition of charity. It is of little benefit to BCAG to replace common law definitions of a charity with a legislative provision, if no similar modernised and simplified definition is introduced covering Public Benevolent Institutions and Deductible Gift Recipients. Again we note the *Report of the Inquiry into the Definition of Charities and Related Organisations* proposed simplifications of definition and of administration in this area.

Recognition of self-help groups

BCAG welcomes the recognition of "open and non-discriminatory self-help groups" as a specific extension of the existing charitable definition under common law. This change may benefit local support groups that are formed by women with breast cancer. BCAG itself meets the general Public Benefit test outlined in Section 7, so the special provision for self help groups is not relevant.

In examining the legislation however it is hard to understand what public policy objectives are met by recognising a small local breast cancer group providing mutual support as a charity, whereas BCAG, which not only provides mutual support but also assists government to improve policy and services for the 10,000 Australian women diagnosed with breast cancer every year might be disqualified.

In conclusion

This legislation would be fairer and better if the government could recognise that empowerment through active participation in decision-making, including influencing government policy, is a crucial and central aspect of a contemporary organisation's charitable purpose.

We suggest that the legislation recognise very clearly that all levels of government and health service delivery now seek the input of organisations like ours as a matter of course. They rightly want us to assist in developing policies, legislation and so on. We undertake this role very willingly on a volunteer basis, as we are committed to improving things for our fellow breast cancer sufferers. Some assistance through being able to attract tax deductible donations would greatly ease our reliance on our members own time, resources and commitment, and we could expand out valued project work for Australian women affected by our disease.

29 August 2003