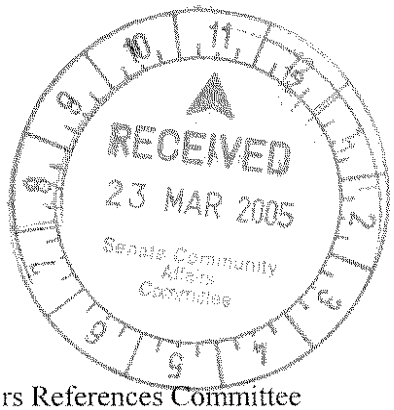

18 March 2005

The Cancer Council Victoria

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

Fax: 02 6277 5829

Senate Inquiry into Services and Treatment Options for Persons with Cancer

The Cancer Council Victoria commends the Senate for endorsing this Inquiry.

The Cancer Council Victoria is an independent volunteer based charity whose core business is cancer control. We conduct and support research, as well as delivering statewide support and prevention programs, and advocating regulation and other interventions to reduce the physical and emotional burden of cancer. We believe that every person with a cancer diagnosis should have access to the best quality treatment and supportive care, and to this end we have been involved in supporting clinical trials research and cancer information and support services for many decades.

The Cancer Council is a member organisation of The Cancer Council Australia, and is an affiliate of both the Clinical Oncological Society of Australia and the National Cancer Control Initiative.

The Cancer Council Victoria is aware of and endorses the joint submission of COSA-TCCA-NCCI. However, we submit some additional comments relating to Term of Reference:

(A) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:
(v) current barriers to implementation of best practice.

Clinical trials research is the foundation of evidence-based treatment. Every new treatment used today was at one time tested in a clinical setting. Clinical trials give patients and other participants access to cutting-edge interventions, and provide researchers with information that will ultimately enable health care providers to prevent and more effectively treat disease. It has been shown that cancer patients who participate in clinical trials generally fare better than patients who do not. Clinical research leads to enhanced health outcomes and provides opportunities to measure efficacy, social and economic costs. A strong clinical research infrastructure, including a comprehensive program of clinical treatment trials in early detection, prevention and treatment is vital to a good health care system.

In order to keep pace with the testing of these new agents, devices and techniques increased resources should be directed toward infrastructure and other support for clinical trials and barriers to participation by both clinicians and patients should be reduced.

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All correspondence and enquiries
1 Rathdowne Street
Carlton Vic 3053
Australia
Telephone: 61 (0)3 9635 5000
Facsimile: 61 (0)3 9635 5270
Email: enquiries@cancervic.org.au
Internet: www.cancervic.org.au

Specific barriers currently inhibiting participation in clinical research include:

- **indemnity insurance for private practice participation in clinical trials**

In Victoria, medical insurers have recently requested private practice oncology specialists to provide extensive documentation for each clinical trial in which they want to enrol their patients, as well as pay an additional premium per annum of approx $5,000. This requirement places an undue burden on limited resources for non-commercial trials in the private sector, especially as it is considered that exposure to litigation in respect to clinical trials is in fact very small. If this becomes a mandatory requirement by medical insurers many private practice oncology specialists will refuse to participate in clinical trials. This will be to the detriment of patient health care. It is considered therefore vitally important that the Federal Government negotiate with private medical insurers to ensure all cancer patients – public and private - have equal opportunity to participate in clinical trial research.

- **institutional human research ethics committee approval for multi-centre research**

The NHMRC National Statement on Ethical Conduct in Research Involving Humans, Draft December 2004 introduces some very welcome amendments. One of which is the statement that an individual Human Research Ethics Committee can accept the decision of another HREC's decision regarding a clinical research trial to be conducted at multiple centres. Multiple reviews of individual research projects by each participating institution's HREC is an inefficient use of resources and unjustly delays commencement of the research, which can result in patients missing out on cutting-edge treatments. We would further support the NHMRC National Statement providing specific guidance as to how the multi-centre research review process can be introduced across institutional HRECs.

- **infrastructure support for non-commercial clinical trial coordination**

The lead-time from a significant laboratory discovery to its use in routine patient management is usually a decade and may be much longer. Therefore, translational research (from laboratory to bedside) and incorporation of results into day-to-day practice are areas deserving long-term support. Supporting oncology specialists – public and private - to participate in clinical trials through provision of clinic-based and central trial management coordination contributes to increased patient recruitment and long-term quality follow-up. This support will result in speedier aggregation of high quality data and new treatments being reported and made available to the patient population sooner. The Federal Government's policy statement "Strengthening Cancer Care", September 2004, and its commitment of $15million to clinical trial research is welcomed. The timely implementation of this policy will greatly contribute to increasing access to non-commercial clinical trials of treatment, devices, techniques and supportive care. We would further support a directive that infrastructure support for clinical research be included as a substantive component of hospital cancer services.

The progressive improvements in cancer cure rates that have occurred over the last half-century would not have occurred without clinical trials of new treatments. Systematic reviews of the results from clinical trials provide the highest level of scientific evidence in the development of evidence-based treatment guidelines. We therefore encourage the Government to implement action in these areas to ensure Australia is able to provide a cancer health care system that is second to none.

Thank you for the opportunity to provide comment to the Inquiry into services and treatment options for persons with cancer.

Yours sincerely

Professor David Hill AM PhD
Director
The Cancer Council Victoria