

THE CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION

2003 ANNUAL REPORT



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Executive Summary

The Canadian Council for Donation and Transplantation (Council) is pleased to present its first annual report, which describes Council's achievements and activities since it first met in October 2001.

Council was created as an advisory body to the federal, provincial and territorial Conference of Deputy Ministers of Health, as an unincorporated association. Council's mandate is to provide advice to the Conference of Deputy Ministers in support of its efforts to coordinate federal, provincial and territorial activities relating to organ and tissue donation and transplantation.

This report highlights Council's achievements since its inception. Council takes pride in these achievements, which have created a foundation of work, which positions Council well for the future.

After putting into place the governance documents defined by its terms of reference, Council began its work by developing strategic objectives and workplans to guide its activities. In December of 2002, from the workplans presented to the Conference of Deputy Ministers, Council was directed to focus on initiatives that would lead to advice on how to improve donation rates and increase the number of transplanted organs and tissues in Canada - the key to narrowing the gap between supply and demand for transplants. These initiatives included:

- Work towards advice on measuring actual and potential donors
- Best practices for the determination and declaration of brain death
- Work towards advice about public awareness and social marketing strategies
- Consideration of ethical issues in organ and tissue donation and transplantation
- Identification of real and perceived barriers to living organ donation

In addition, Council continued on with other work that was in progress including:

- Development of an understanding of the supply and need for allograft tissues in Canada
- A costing and economic analysis of the functions necessary to provide tissue for transplant in Canada
- In response to public concerns about safety related issues in tissue transplantation in 2002, Council provided advice to the Conference of Deputy Ministers on how the safety of transplanted tissues may be protected and enhanced.

These important initiatives were addressed enthusiastically by Council and are either completed or in an advanced state of progress. Many current initiatives form the basis for further work, to be addressed in a two-year workplan that Council plans to present to the Conference of Deputy Ministers in the spring of 2004.

In the process of developing advice for the Conference of Deputy Ministers, Council has spearheaded many initiatives ranging from conferences and workshops to consultation sessions and surveys. These initiatives, many the first of their kind in Canada, have allowed experts to come together and discuss issues surrounding organ and tissue donation and transplantation. Some examples were the first national forum on Severe Brain Injury to Neurological Determination of Death, which was hosted by Council in April of 2003. Another, in September 2002 was the first meeting of the heads of the four largest provincial organ procurement organizations to discuss issues of common interest, and to develop collaborative relationships.

On January 13, 2004, Dr. Philip Belitsky resigned from his position as the inaugural Chair of Council. Council members thank Dr. Belitsky for his commitment and hard work in leading Council through its formative stages.

Background

The Council was established by the federal, provincial and territorial Conference of Deputy Ministers of Health (the Conference) in October of 2001 in response to two reports¹ that highlighted concerns about a persistent and growing gap between the supply of and demand for organs and tissues for transplantation in Canada. Both reports proposed the development of a national strategy to address this issue, including the formation of a council of experts which would assist in developing and monitoring this strategy.

“The appointment of the members to the Canadian Council for Donation and Transplantation is a key step in increasing organ and tissue donation in Canada. This Council will provide advice on a national strategy to enhance organ and tissue donation and transplantation across the country, aimed at significantly improving organ donor rates, maximizing the support provided to donor families and enhancing transplantation services in this country.”

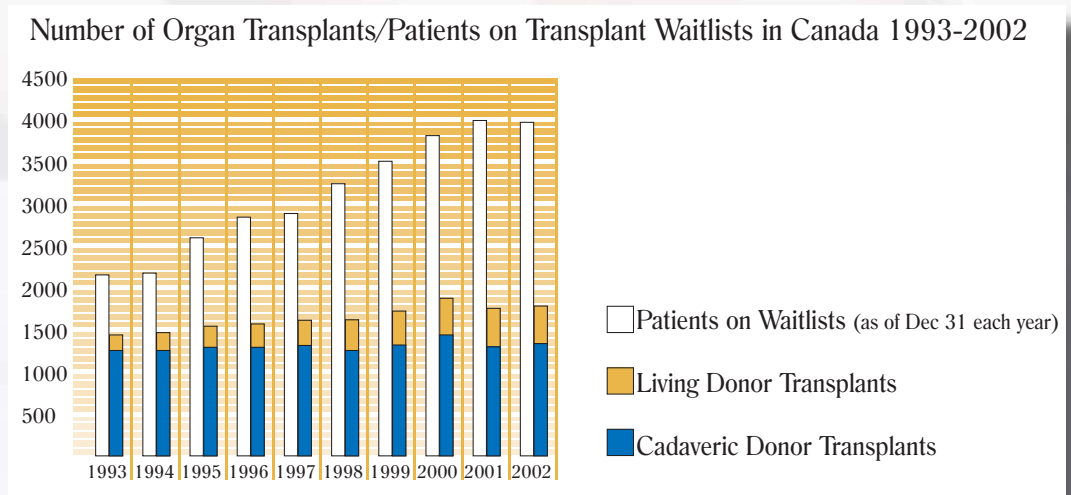
- Former Health Minister Allan Rock,
August 20, 2001

The Council formed three Standing Committees reflecting the main components of the Canadian organ and tissue donation and transplantation system: donation, organ transplantation, and tissue banking and transplantation. Membership of the committees consists of Council members and non-Council experts to augment the expertise relative to that area of focus.

The Council has identified three strategic objectives to frame its work.

1. Canadians have the opportunity to participate in the donation process and their contribution is recognized and valued.
2. Canadians in need of a transplant have timely and fair access to organs and tissues.
3. Canadians have positive health outcomes and an improved quality of life as a result of the donation and transplantation process.

The Committees have developed specific initiatives related to these objectives to generate advice for consideration by the Conference.



¹ Organ and Tissue Donation and Transplantation: A Canadian Approach. April 1999. House of Commons Standing Committee on Health and A Coordinated and Comprehensive Donation and Transplantation Strategy for Canada. November 1999. National Coordinating Committee for Organ and Tissue Donation, Distribution and Transplantation.

Priorities identified by the Conference of Deputy Ministers

The primary issue identified in Canada with respect to organ and tissue donation and transplantation is the need to increase donation rates. For over a decade the shortage of donor organs and tissues in Canada has limited the opportunity for life saving or enhancing transplant procedures.

To improve donation rates in Canada, three broad areas need attention:

- A method that is simple, reliable, and reproducible to define, measure, and monitor donation rates.
- Strategies to ensure that the public not only supports donation in principle, but that Canadians take steps towards donation as a concrete individual and family consideration.
- A review and change, where appropriate, of the existing structures, relationships, standards and practices, by health care professionals and institutions, to optimize the number of donations and transplants.

The Conference asked Council to treat donation related issues as a priority in developing advice to the Conference. The following section provides an overview of the Council's achievements to date in this priority area.

“At the present time, there is a serious shortage of organ and tissue donors available in relation to numbers needed. More than 3,500 Canadians are waiting for an organ transplant, and every year nearly 150 of them die while waiting. The need for organ and tissue donors will only increase in the future because of an ageing population.”

- Organ and Tissue Donations: Canadian Public Awareness, Knowledge and Attitudes. 2001. Environics Research Group Ltd.

Measuring Actual and Potential Donation Rates

A key requirement to determining success in improving donation rates in Canada is to measure changes in the gap between **actual** and **potential** organ and tissue donation rates. Ideally the measure used would be easily understood, economical, and readily reproducible in all jurisdictions and institutions.

Currently, the number of **actual** donors per million population is the most widely reported measure of **organ** procurement. However, this figure does not indicate the number of **potential** donors in the population. The establishment and adoption of a realistic potential donation rate for Canada will provide a benchmark against which actual donations can be measured. This will allow effective analyses of any gaps between potential and actual donation rates, and will allow for measures to improve donation rates.

Council is working with the Canadian Institute for Health Information to determine the reliability of several existing data sources, which could serve to determine a realistic potential donor rate for Canada, and how to accurately measure it. As a first step, a report entitled, *Estimating Potential Tissue Donors in Canada from 1995-2000: An Exploratory Analysis Using Acute Care Hospital Admissions Data* was completed which describes a possible approach to estimating potential tissue donors.

Best Practices for the Determination and Declaration of Brain Death

Currently, all Canadian provinces and territories legally define brain death "according to accepted medical practice". However, substantial variability exists in the recognition, diagnosis and documentation of brain death by medical practitioners in the field. Inconsistencies in both the identification and management of patients with severe brain injury, who may evolve to brain death, limit the number of organs available for transplantation.

In April 2003, the Council hosted the first national forum on Severe Brain Injury to Neurological Determination of Death, which focused specifically on the care of patients with severe brain injuries that result in brain death. For the first time, specialists were brought together from across Canada representing a wide spectrum of health related organizations including nursing and medical professionals in critical care, emergency, trauma, neurosurgery, neurology, donation, transplantation, health law, and bioethics.

The outcome of the forum was consensus on the determination, diagnosis, declaration, and documentation of brain death.

The forum process has resulted in key background documents, including literature reviews and surveys creating comprehensive national data, not available before, from which to initiate future discussions. New and relevant data and forums such as this provide groups that have never had the occasion to meet with the opportunity to share information, discuss related issues, and focus on recommendations to improve practice.

Public Awareness and Social Marketing Strategies

Two public opinion polls sponsored by Council confirmed that Canadians broadly support organ and tissue donation and transplantation. However, less than half of those in support sign donor cards or discuss their choice with their families, resulting in loss of potential donors. Effective public awareness and social marketing strategies need to focus on converting passive support into actual behaviours that will increase donation.

Council commissioned a review of existing public awareness and public education activities related to organ and tissue donation in Canada. The review revealed a relatively fragmented approach across jurisdictions and organizations. The majority of those contacted suggested a more collaborative approach would be useful. Council will utilize the information from the review and from a number of stakeholder consultations to develop a recommended framework as advice to the Conference for more coordinated and effective approaches to public awareness and education. Given Canada's ethnic diversity, Council has also formed a working group to examine ethno-cultural considerations for public awareness and social marketing in the area of organ and tissue

Participants of the 2003 Forum: Severe Brain Injury to Neurological Determination of Death

Alberta Health and Wellness, British Columbia Transplant Society, Canadian Association of Critical Care Nurses, Canadian Association of Emergency Physicians, Canadian Association of Neuroscience Nurses, Canadian Association of Transplantation, Canadian Bioethics Society, Canadian Congress of Neurological Sciences, Canadian Critical Care Society, Canadian Hospice and Palliative Care Association, Canadian Institute for Health Information, Canadian Medical Association Journal, Canadian Medical Protective Association, Canadian Neurological Society, Canadian Neurosurgical Society, Canadian Nurses Association, Canadian Organ Replacement Registry, Canadian Society of Transplantation, Collège des Médecins du Québec, College of Family Physicians of Canada, College of Physicians and Surgeons of British Columbia, Chief Coroners and Medical Examiners of Canada, Health Canada, National Emergency Nurses Affiliation, Nova Scotia Department of Health, Quebec Society of Intensivists, Québec Transplant, Trauma Association of Canada, Trauma Coordinators of Canada, Trillium Gift of Life Network, Urban Futures Institute

“I have been dedicated to the cause of treating end-stage kidney failure since 1960, and kidney transplantation since 1963. I realized some time ago that the health professions -- specifically, medicine, nursing, etc. -- were not able to solve the supply/demand situation for organs and tissues through professional activity. The solution must lie in public awareness, public education, and enlightened government action. I therefore welcomed the chance to be a member of something new – the Canadian Council for Donation and Transplantation approach.”

- John B. Dossetor, MD, Ottawa, Ontario, CCDT Council Member

Other Important Initiatives

In addition to the work performed under the priorities identified by the Conference, Council also explored other issues important to organ and tissue donation and transplantation in Canada. Several initiatives were undertaken in the area of tissue banking and transplantation, while others were of overarching importance across the entire organ and tissue donation and transplantation arena.

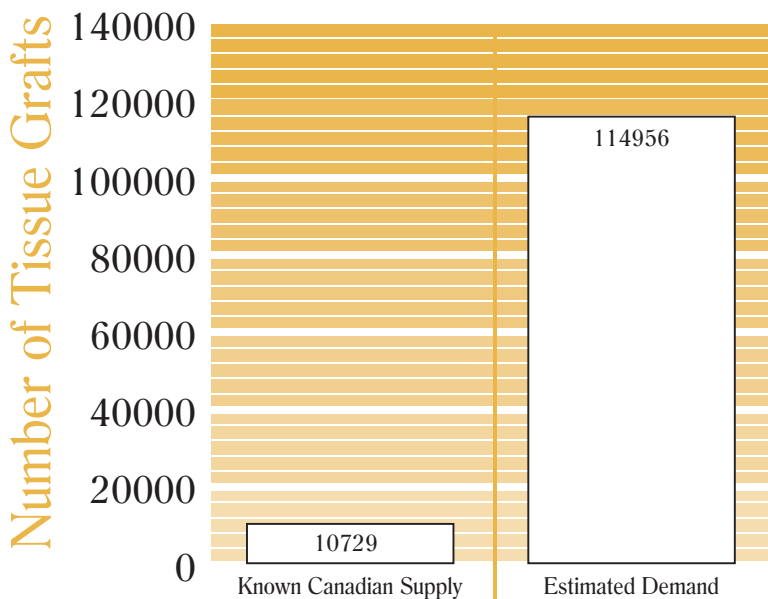
Tissue Banking and Transplantation

Tissue banking in Canada could generally be described as fragmented and underdeveloped, with room for improvement in serving Canadians in need of tissue transplants. Until now, there has been little information about tissue banking in Canada. Groundbreaking work by the Council has provided information that can be incorporated into future advice regarding a suitable business model for tissue banking in Canada.

Supply and Demand of Human Allograft Tissue in Canada

Investigation into the supply and demand of human allograft tissue in Canada was an important primary step in understanding the existing situation of tissue banking activities in the country. Known Canadian tissue banks participated in a survey to quantify the supply of human allograft tissues available from Canadian sources. A wide range of surgical specialists was surveyed with the results demonstrating a very large gap between the supply and demand for human allograft tissues. An interesting finding was that Dental surgical users account for approximately half the amount of tissues used. The large gap between supply and demand appears to be filled by purchasing tissues from foreign sources and resorting to alternative medical procedures.

Supply and Demand for Human Allograft Tissues in Canada



Human Tissue Banking in Canada – Costing and Economic Analysis

In developing a potential business model for tissue banking, a comprehensive understanding of the economics of operating tissue banks in Canada was required. Work was undertaken to determine the types and magnitudes of the costs to operate a tissue bank. The results will be used to analyze and improve current cost recovery fee structures and to compare Canadian tissue costs to costs from foreign tissue providers. The information gathered from this project will be incorporated into future advice regarding a business model for tissue banking in Canada.

Bringing Together Canada's Provincial Donor Organizations

As part of its mandate to provide advice that would assist the Conference in coordinating its activities in donation and transplantation, Council initiated opportunities to bring provincial organizations together to identify areas of common interest, support and collaboration.

As a first step, the Chair of Council initiated a meeting with the heads of the four largest provincial organ procurement organizations and programs on September 11, 2002 in Toronto. The meeting established formal interaction between the participants, and also identified two important areas for Council to implement:

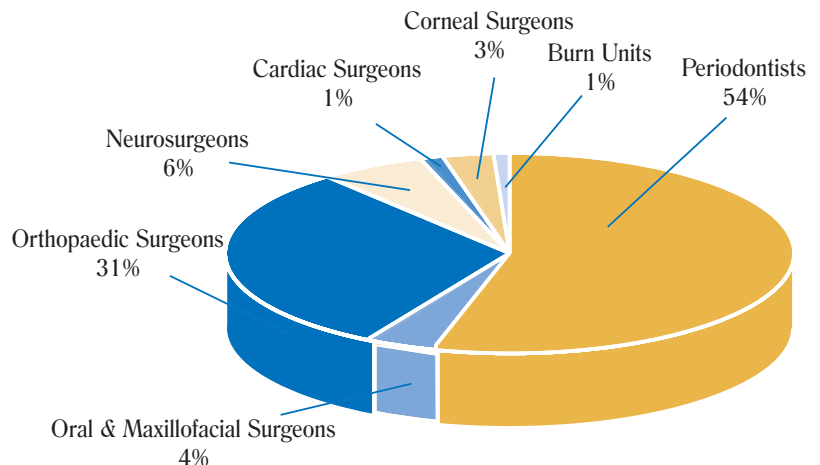
1. A consensus conference on living donation to be hosted in June 2004, focusing on identifying barriers and developing strategies to eliminate or overcome them.
2. Formation of an ad-hoc committee to address ethno-cultural differences in attitudes to organ and tissue donation.

In the future Council intends to expand these discussions to include all provincial organ procurement organizations in Canada.

“The Tissue Committee has in its short tenure together been able to bring forth information and key stakeholders in the field to provide a clear understanding of the scope of the demand for allograft tissues and the existing and potential supply of allograft tissues for Canadian patients. This is important work in moving forward to ensure all Canadians have appropriate access to safe allograft tissues.”

- James Mohr, Halifax, Nova Scotia, Head
- CCDT Tissue Committee

Current Demand for Allograft Tissue by User Groups



Response to Emerging Issues

In addition to working on projects approved by the Conference, the Council has assumed a role to inform and provide advice to the Conference on emerging issues that would impact organ and tissue donation and transplantation. Recent news events involving the investigation and in some cases the closure or suspension, of specific tissue banks in Canada and the United States brought forth issues related to the safety and quality of tissues provided for transplantation in Canada. The Council responded to these issues by providing advice in the autumn of 2002 followed up with further advice in the spring of 2003 on strategies to improve and ensure the quality and safety of tissues transplanted in Canada.

Privacy Issues

A report has been prepared on how current access to information and privacy protection legislation may impact organ and tissue donation and transplantation, as well as research, data collection and sharing information. As background information for all of Council's initiatives, this report deals with areas such as the emerging movement towards electronic health records, including organ and tissue donation and transplantation, as well as potential privacy concerns associated with the development of donor registries.

Jurisdictional Accountability

There is a broad consensus that the popular support for, and the credibility of, the organ and tissue donation and transplantation systems in Canada depends significantly on the reporting of results and outcomes. A report was commissioned on Jurisdictional Accountability to examine existing accountability mechanisms in all Canadian jurisdictions as they relate to donation and transplantation. The report describes the primary roles of governments in this field, and what accountability and accreditation mechanisms are in place to monitor outcomes. It is expected to assist Council in developing advice regarding best accountability practices as part of a national strategy to enhance the organ and tissue donation and transplantation system in Canada.

“The Council Donation Committee has been an excellent opportunity to pull together various stakeholders from across the country who share the same goals and commitment about increasing organ and tissue donation. This is the first time we have been able to do this in Canada and our work so far shows how when individuals and groups are brought together and provided with sufficient resources, powerful results can be achieved that will have a positive impact on the donation rate in this country. I am delighted to be working with such a dynamic group of people.”

- Rosalie Starzomski, RN, PhD, Vancouver,
British Columbia, CCDT Donation Committee Member

Overview of the Canadian Council for Donation and Transplantation

Council

The Council is comprised of 15 members plus a Chair that include representatives of key professional donation and transplantation organizations, non-governmental organizations, the ethics community, spiritual and pastoral care community, representatives of transplantation recipients, and donor families. Reflecting the broad diversity of Canada, the members were selected for their expertise and knowledge of organ and tissue donation and transplantation.

Council currently has three vacancies that will be filled pending the final report of the Council's operational review and the associated recommendations from the Conference.

Secretariat

The Council is supported by a Secretariat, which is responsible for the day-to-day administration of Council. This includes the organization of meetings and phone calls, taking and distribution of minutes, preparation of correspondence and reports, and contract and financial administration.

As Council became established, it became evident that the Standing Committees were in need of project management support. To meet this need, the Secretariat provides the Committees with project managers that have both content specific knowledge and project management experience.

Standing Committees

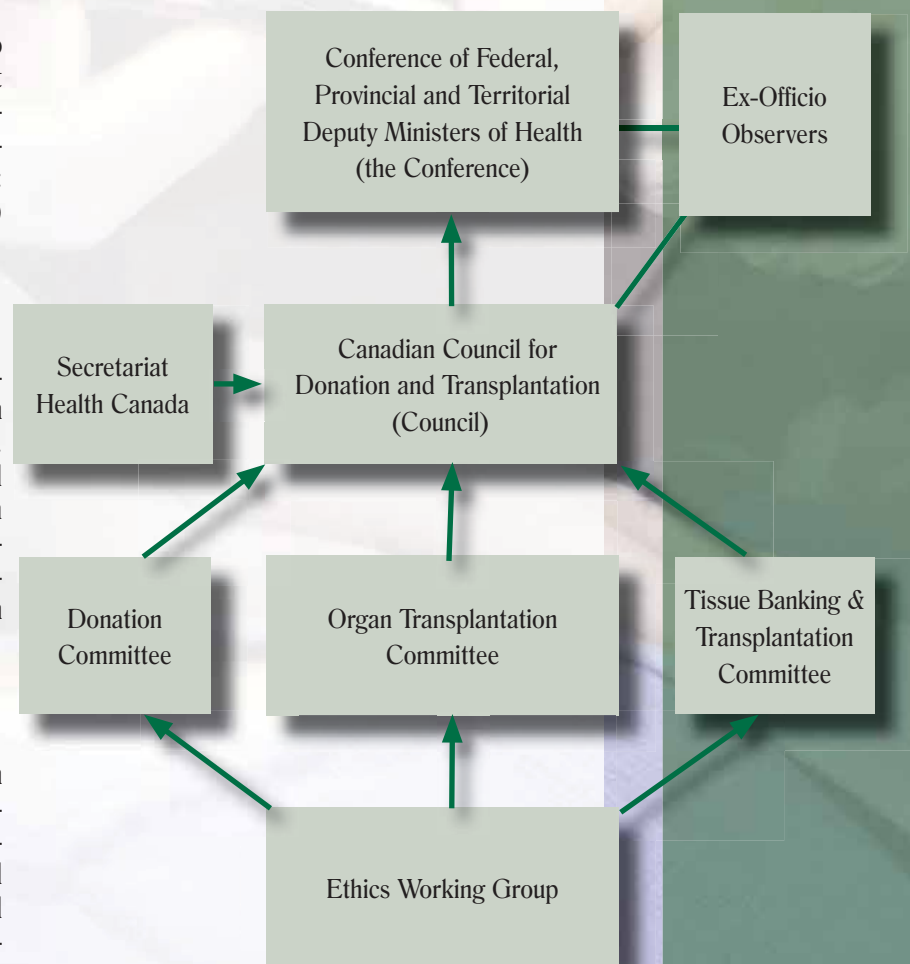
The purpose of the Standing Committees is to bring to Council standards, policies and best practices for review and ratification. Strategically, the Council formed three Standing Committees that focus on specific areas of expertise: 1) Donation, 2) Organ Transplantation and 3) Tissue Banking and Transplantation.

Ethics Working Group

The Ethics Working Group supports and facilitates the Council and the three committees in their identification and analysis of ethical issues. The Group also provides guidance to Council on overarching ethical issues related to organ and tissue donation and transplantation. Representatives from the Donation, Organ Transplantation and Tissue Banking and Transplantation Committees form this working group.

Ex-officios

Ex-officio observers serve as liaison between Council and the government, region or committee they represent. Their role is to provide information to the Council on existing or planned policies and programs regarding donation and transplantation within their jurisdictions. Ex-officios may be requested to provide advice to the Council on workplan initiatives or to help in drafting recommendations to the Conference.



The Canadian Council for Donation and Transplantation

COUNCIL MEMBERS

Eugene Bereza, MD, (Tissue, Ethics)
Montreal, Quebec

Rabbi Dr. Reuven Bulka, PhD, (Donation)
Ottawa, Ontario

Diane S. Craig, (Donation)
Ottawa, Ontario

Christopher Doig, MD, (Donation)
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John Dossetor, MD, (Organ Transplantation, Ethics)
Ottawa, Ontario

Edward A. Ferre, (Tissue)
Vancouver, British Columbia

David Hollomby, MD, (Organ Transplantation)
London, Ontario

James William Mohr, (Tissue)
Halifax, Nova Scotia

Sheilagh Ross, (Donation)
Camrose, Alberta

Graham Scoles, PhD, (Tissue)
Saskatoon, Saskatchewan

Sam D. Shemie, MD, (Donation)
Montreal, Quebec

Rosalie Starzomski, RN, PhD, (Donation, Ethics)
Vancouver, British Columbia

NON COUNCIL COMMITTEE MEMBERS

Max Bishop, RN, (Donation)
St. Johns, Newfoundland

Paul Byrne, MD, (Donation)
Edmonton, Alberta

Fides Coloma, RN, (Tissue)
Toronto, Ontario

Raffaele Forcione, (Donation)
Montreal, Quebec

Marc Germain, MD, (Tissue)
Sainte-Foy, Quebec

Diane Hebert, MD, (Organ Transplantation)
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Jonathan Lakey, PhD, (Tissue)
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Robert Levy, MD, (Organ Transplantation)
Vancouver, British Columbia

Vivian McAlister, MD, (Organ Transplantation)
London, Ontario

Ted Meeking, (Organ Transplantation)
Toronto, Ontario

Katrin Nakashima, (Organ Transplantation)
Westmount, Quebec

FORMER COUNCIL MEMBERS

Philip Belitsky, MD,
Halifax, Nova Scotia.

Heather Ross, MD,
Toronto, Ontario

Rolf Loertscher, MD,
Montreal, Quebec

Heather Stoyles, RN,
Halifax, Nova Scotia

FORMER NON COUNCIL MEMBERS

Michael Gross, MD,
Halifax, Nova Scotia

Kathy Jackson, RN,
Edmonton, Alberta

Financial Summary

Fiscal Year	2001-2002	2002-2003	2003-2004*
Budget	3,818,000	3,818,000	3,818,000
Distribution of Funds			
Secretariat	488,318.89	507,120.15	470,000
Council	-	595,835.31	534,000
Public Awareness**	2,469,000		
Initiatives			
• Donation		251,853.63	950,000
• Organ Transplantation		101,506.38	200,000
• Tissue Banking and Transplantation		114,840.38	229,191.40
• Overarching		35,349.58	5,000.00
Subtotal Initiatives		503,549.97	503,549.97
Business Planning		82,264.39	
Total Expenditures	2,975,318.89	1,688,769.82	2,388,191.40
Surplus/(Deficit)	860,681.11	2,129,230.18	1,429,808.60

Notes:

* Estimated expenditures

** Council became active in the second half of the 2001-2002 fiscal year (CCDT members were appointed in August 2001, and the first Council meeting was held in October 2001). As a result a significant portion of the Council's annual budget was at risk of lapsing, therefore \$2.469 million was allocated to fund a public awareness campaign for 2002-2003. The funds were committed before the end of the 2001-2002 fiscal year to fund a campaign beginning in April 2002.