



THE CANADIAN COUNCIL FOR DONATION AND TRANSPLANTATION

2004 ANNUAL REPORT



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This report is a product of the work performed by the Canadian Council for Donation and Transplantation and its Committees. Funding for this publication was provided by Health Canada. The opinions expressed in this publication are those of the authors/ researchers and do not necessarily reflect the official views of Health Canada.

Message from the Chair

This past year marked a new phase for the Canadian Council for Donation and Transplantation (CCDT) as it turned the corner from organizational start-up. In 2004, the CCDT moved to address some outstanding developmental issues. Prompted by external evaluation findings (BearingPoint Report), the CCDT began addressing concerns related to governance, collaboration, evaluation, accountability and communications. These activities have strengthened the CCDT in terms of efficiency and effectiveness.

The CCDT work plan was revised in 2004. At the request of the Federal/Provincial/ Territorial Conference of Deputy Ministers of Health (CDM), the CCDT prepared a two year work plan and strategic framework (2004/05-2005/06). The subsequent approval by the CDM in June 2004 launched CCDT work on thirty-two project initiatives.

The CCDT is also pleased to welcome new Council members. Following resignations in late 2003 and early 2004, Michele Lahey, Dr. Vivian McAlister and Dr. Marc Germain were appointed to Council. Their extensive experience within the health system in nursing, organ transplantation and tissue banking and transplantation provide an important complement to Council.

The CCDT has fresh commitment to many exciting initiatives. Through hard work and dedication of Council and staff members, 2004 saw numerous achievements and the forwarding of advice to the CDM in the area of organ and tissue donation and transplantation.

Many achievements and milestones were reached by the CCDT in 2004. A significant number of partnerships and stakeholder relationships were realized through initiative activities. In the area of donation, the CCDT focused on activities related to social marketing and public awareness, working with ethnocultural and religious communities, maximizing donor organ potential, and establishing best practices for the determination and declaration of brain death. In the area of organ transplantation, the CCDT has undertaken work related to live organ donation. And in the area of accountability, the CCDT has completed work related to reporting standards for donor activities and transplantation data sets. Initiatives related to tissue banking and transplantation have also resumed and initial deliverables are scheduled for completion early next year.

Clearly, it has been a busy year offering both challenges and opportunities. I invite you to learn more about the CCDT and our exciting efforts as described in the 2004 Canadian Council for Donation and Transplantation Annual Report.

Sincerely,

Leah Hollins
Council Chair

Background

In September 1999, the federal, provincial and territorial Ministers of Health agreed to formulate a coordinated federal/ provincial/ territorial strategy to improve the organ and tissue donation and transplantation in Canada. They were responding to two reports¹ that highlighted concerns about a persistent and growing gap between the supply and demand for organs and tissues for transplantation in Canada. Both reports proposed the development of a national strategy and the formation of a council of experts to assist in developing and monitoring of the strategy.

A key component of the strategy was establishing the CCDT in October 2001. The CCDT was established as an advisory body to the CDM in support of its efforts to coordinate federal, provincial and territorial activities relating to organ donation and transplantation. The authority to make decisions with respect to organ and tissue donation and transplantation remains with the federal /provincial /territorial governments.

The CCDT activity will see Council develop organ and tissue donation and transplantation advice in areas such as:

- A coordinated federal/ provincial/ territorial strategy and high quality provincial/territorial strategies
- Standards and clinical practice guidelines based on leading/best practices
- Public awareness and social marketing strategies and their implementation
- Federal/ provincial/ territorial information/ data management systems
- Educational resources for interdisciplinary professionals involved in donation and transplantation processes
- A system to monitor the performance in Canada against other jurisdictions
- A system to monitor progress in relation to implementation targets, and
- An ongoing process to identify emerging issues and link to the strategic process

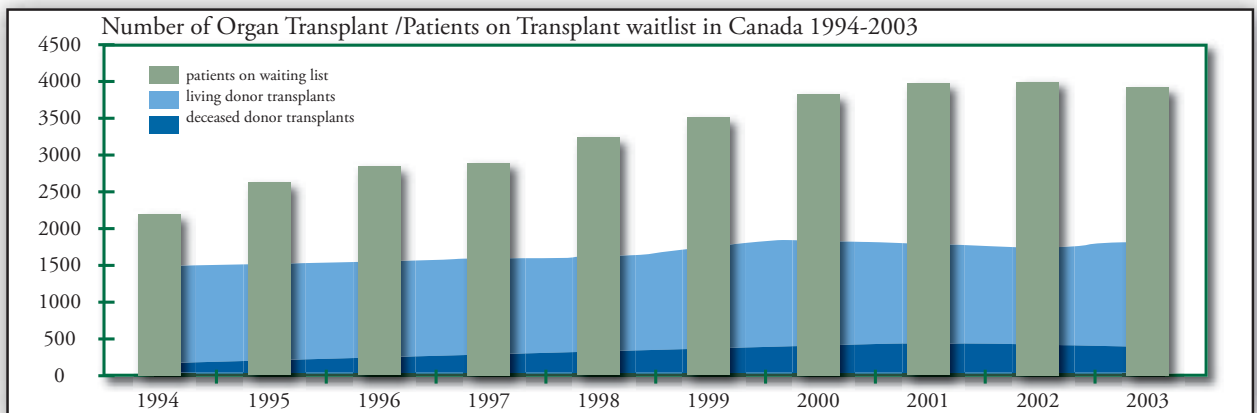
A number of Standing Committees are utilized to direct the work of the CCDT. Three Standing Committees, namely Donation, Organ Transplantation, and Tissue Banking and Transplantation reflect the main compo-

nents of the Canadian organ and tissue donation and transplantation system. A fourth Standing Committee, the Liaison Committee, facilitates cross-committee communication and directs collaboration on overarching initiatives such as ethics and the law, data collection and accountability issues. Committee membership includes Council members and non-Council experts who augment expertise relative to the area of focus. The Council also uses a Governance Working Group which supports internal processes related to leadership, review and revisions of governance documents and policy development.

The CCDT developed a strategic framework for donation and transplantation in Canada to guide its work in preparing and providing advice to the CDM. The strategic framework identifies the major components of organ and tissue donation and transplantation in Canada, and the key challenges, which need to be met to achieve improvements. The framework is designed around the way Canadians interact with organ and tissue donation and transplantation, as donors, recipients, health professionals and members of the general public. The framework also considers overarching issues such as ethics, professional support and education, information gathering and dissemination, as well as system accountability.

In its work the CCDT aims to develop and provide advice, for CDM consideration, that would form the foundation for a coordinated federal/ provincial/ territorial strategy to improve organ and tissue donation and transplantation in Canada, with the following long-term expected outcomes:

- 1 Number of intended donors is maximized.
- 2 Number of organs and tissues recovered from donors is maximized.
- 3 Transplant outcomes are optimized including the development of transparent and equitable criteria for referring and listing potential transplant recipients and for allocating organs and tissues.
- 4 Relevant information is available to promote best practices and to enhance the credibility of donation and transplantation.



Includes all organ transplants performed in Canadian hospitals and registered in CORR. Waiting list includes active and on-hold patients and excludes patients waiting for islet cell transplants. Source: Canadian Organ Replacement Register, Canadian Institute for Health Information (2004).

¹Organ 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.

STRATEGIC FRAMEWORK FOR DONATION AND TRANSPLANTATION IN CANADA: MODEL

DONATION (DONOR)			TRANSPLANTATION (RECIPIENT)		DONATION AND TRANSPLANTATION
PUBLIC	HEALTH SYSTEM				PUBLIC
INTENDED DONOR	POTENTIAL DONOR	ACTUAL DONOR	REFERRAL ASSESSMENT LISTING	TRANSPLANTATION FOLLOW-UP	ACCOUNTABILITY
<p>CHALLENGES:</p> <p>Develop and build support for organ and tissue donation, in consideration of Canada's diversity.</p> <p>Encourage Canadians to turn this support into action by expressing their intent to donate.</p>	<p>CHALLENGES:</p> <p>Deceased:</p> <ul style="list-style-type: none"> ■ To identify and refer all potential donors. ■ To explore all potential sources of non-living donations. ■ To maximize the number of organs and tissues provided by actual donors. <p>Living:</p> <ul style="list-style-type: none"> ■ To explore opportunities and challenges of living donation as a legitimate and accepted source of transplantable organs and tissues. <p>Tissue Banking:</p> <ul style="list-style-type: none"> ■ To develop a service delivery model with the capability to safely recover, process and distribute tissues from all potential donors. 		<p>CHALLENGES:</p> <p>Transplantation:</p> <ul style="list-style-type: none"> ■ To optimally support and refer potential transplant recipients. ■ To assess and list patients waiting for transplants based on common and transparent criteria. ■ To optimally monitor and evaluate transplant recipients. ■ Optimize organ utilization and allocation. 		<p>CHALLENGES:</p> <p>To measure and report on outcomes to:</p> <ul style="list-style-type: none"> ■ Promote the development and adoption of best practices. ■ Demonstrate the efficacy of the donation and transplantation system to donors, recipients, health providers, stakeholders, governments and the Canadian public.
OVERARCHING ISSUES: ETHICS, PROFESSIONAL SUPPORT AND EDUCATION, INFORMATION GATHERING AND DISSEMINATION					
FINAL OUTCOME Number of intended donors maximized.	FINAL OUTCOME Number of organs and tissues recovered from donors is maximized.		FINAL OUTCOME Transparent and equitable criteria for referring and listing potential transplant recipients and for allocating organs and tissues, and to optimize transplant outcomes.		FINAL OUTCOME Relevant information is available to promote best practices and to enhance the credibility of the system.

GLOSSARY

INTENDED DONOR:

Someone who has clearly identified his/her intent to become a donor by signing a donor card or asking to be listed on a registry and who has discussed his/her decision with their family.

POTENTIAL DONOR:

Someone who has died and consent for donation has been obtained, or someone who is alive and has been approved for donation. Organs and/or tissues may be recovered.

ACTUAL DONOR:

Someone who has actually donated at least one organ or tissue, and one organ or tissue has been transplanted, or tissues which have been deemed transplantable were banked.

REFERRAL AND ASSESSMENT:

The processes whereby individuals are referred to a transplant program and by which their suitability for transplantation is assessed.

LISTING:

The process for placing an individual on a waitlist to receive a transplant and to manage that individual's rank and status on the waitlist.

ALLOCATION:

The process to allocate a donor organ or tissue to a waitlist candidate.

TRANSPLANT FOLLOW-UP:

The process of monitoring and evaluating the ongoing health and organ function of organ transplant recipients.

ACCOUNTABILITY:

Measurement and reporting of outcomes to demonstrate that donation and transplantation processes are fair and transparent.

Reflection and Renewal

■ The CCDT has marked many achievements and milestones since its inception in the fall of 2001. As a new organization it has also experienced some challenges, and 2004 was a year of organizational reflection and renewal.

During the past year, the CCDT experienced several changes to Council membership. In January 2004, the inaugural Chair, Dr. Philip Belitsky, resigned from Council. The CDM asked Leah Hollins to serve as Interim Chair for three months, and later Council extended the appointment to December 31, 2004. As previously mentioned, Michele Lahey, Dr. Vivian McAlister and Dr. Marc Germain were appointed into vacancies on Council bringing extensive experience within the health system, in nursing, organ transplantation and tissue banking and transplantation.

In 2004, the CCDT received and responded to an external evaluation, commissioned by the CDM, of its design, delivery and implementation. The evaluation report entitled, Evaluation of the Effectiveness and Efficiency of the Canadian Council for Donation and Transplantation (BearingPoint Report), provided thirty-three recommendations to improve the effectiveness and efficiency of the CCDT. Following release of the findings, the CCDT prepared a detailed response to the relevant recommendations as requested by the CDM. In June 2004, the CDM accepted the proposed plan of action which addressed such areas as governance, collaboration, evaluation, accountability and communications.

The CCDT work plan was also reviewed and revised in 2004 following a gap in initiative work while the external evaluation was being conducted. At the CDM's request, the CCDT prepared a two-year work plan and strategic framework (2004/05-2005/06). The subsequent approval by the CDM in June 2004 launched CCDT work on thirty-two project initiatives.

During deliberations at its June 2004 meeting, the CDM also requested that recommendations regarding implementation strategies be added to the components of advice provided by the CCDT. The CCDT welcomed the opportunity and appreciated the level of confidence in its capacity. Currently, the CCDT is engaged in preliminary strategic work planning in the area of implementation strategies.

Partnerships and Stakeholders

CCDT initiatives require strong collaboration. Partners and stakeholders are engaged in CCDT activities as non-Council committee members; as representatives on initiative steering committees; through stakeholder consultations on knowledge development; through forum attendance where recommendations are developed; and through distribution of information. The CCDT partners with various types of organizations including organ procurement organizations, professional societies, critical care facilities, hospitals, health authorities, provincial and federal government departments, transplant programs, health and research organizations, universities and allied health organizations. Partners and stakeholders commit many volunteer hours toward the achievement of CCDT initiatives.

A welcome result of the CCDT's hard work and progress on initiatives over the last few years is the high level of interest shown by partners and stakeholders. The CCDT now enjoys participation requests from organizations wanting to get involved.

CCDT Partners and Stakeholders

Organ Procurement Organizations, Eye and Tissue Banks, Critical Care Facilities, Transplant Hospitals, Universities, Provincial Government Departments, particularly Provincial Health Ministries, Provincial and Regional Health Authorities, Federal Government Departments, particularly Health Canada, Canadian Anesthesiologists' Society, Canadian Association of Critical Care Nurses, Canadian Association of Emergency Physicians, Canadian Association of Neuroscience Nurses, Canadian Association of Tissue Banks, Canadian Association of Transplantation, Canadian Bioethics Society, Canadian Congress of Neurological Sciences, Canadian Critical Care Society, Canadian Hospice and Palliative Care Association, Canadian Institute of Health Information, Canadian Organ Replacement Registry, Canadian Kidney Foundation, Canadian Liver Foundation, Canadian Neurocritical Care Group, Canadian Neurological Society, Canadian Nurses Association, Canadian Society of Transplantation, Chief Coroners and Medical Examiners of Canada, Collège des Médecins du Québec, College of Family Physicians of Canada, Heart and Stroke Foundation of Canada, International Society for Heart and Lung Transplantation, National Emergency Nurses Affiliation, Quebec Society of Intensivists, Trauma Association of Canada, Trauma Coordinators of Canada, United Network for Organ Sharing, Urban Futures Institute.

PARTNERSHIPS AND STAKEHOLDERS

"Moving toward a true systems approach to organ and tissue donation and transplantation in Canada is a complex and difficult task. The CCDT is working hard to develop productive working relationships with our many partners in this task."

Dave Hollomby, MD, London, Ontario
Chair, Organ Transplantation Committee, CCDT

Initiatives

■ The initiatives of the CCDT are designed to develop and provide advice to the CDM on ways to meet the key challenges of organ and tissue donation and transplantation in Canada.

Given the complexity of the system, many of the CCDT's initiatives are multi-year, multi-phase, multi-stakeholder projects. Final advice to the CDM could be based on any or all of the following components: literature reviews, reports, consultations, focus groups, stakeholder forums, cost analysis, public surveys, legal and jurisdictional reviews and evaluations.

Another key outcome of some CCDT initiatives is the impact on clinical practice that is starting to take hold. Recommendations and findings developed from consultations and forums of experts in the area of organ and tissue donation and transplantation are starting to be recognized and implemented in Canadian clinical settings.

While the CCDT initially focused on donation related initiatives as per the CDM's request, it is now actively working in the areas of organ transplantation and tissue banking and transplantation. This year, the CCDT reached numerous milestones in the donation area related to social marketing and public awareness, working with ethnocultural and religious communities, maximizing donor organ potential, and establishing best practices for the determination and declaration of brain death. In the area of organ transplantation, the CCDT has undertaken work related to live organ donation. And in the area of accountability the CCDT has completed work related to reporting standards for donor activities and transplantation data sets. Initiatives related to tissue banking and transplantation are also underway and initial deliverables are scheduled for completion early next year.

"There is a growing scrutiny with regard to tissue availability and safety in our country, especially with the recent publication of industry standards by the Canadian Standards Association.

Because of this, the tissue banking environment is rapidly evolving in Canada.

The CCDT will likely play an important role in the final result of this transformation."

*Marc Germain, MD, PhD.
Vice-President, Histo- Québec*

CCDT Council Member and Tissue Banking and Transplantation Committee Member

"The Canadian Council for Donation and Transplantation has shown initiative and leadership in developing conferences and guideline documents incorporating the views of key stakeholders regarding neurological determination of death, medical management of organ donors, and organ donation after cardiac death. These proceedings have been very well planned and executed, have provided a much needed national consensus in these areas, and are being incorporated into our practices to increase quality and standardization of care in Ontario. Donation and transplantation in Canada has been measurably improved by the efforts of the Council, and we look forward to ongoing collaboration in these areas."

Dr. Cameron Guest, MD
Chief Medical Officer
Trillium Gift of Life Network

Impacting Clinical Practice

In the course of formulating findings and advice for the CDM, the CCDT provides a forum for experts from across Canada and abroad to discuss issues of common interest and to develop consensus positions on a variety of issues. This broad expert consensus building is starting to impact clinical practice and establish the CCDT as a key player in the Canadian organ and tissue donation and transplantation stakeholder community.

For example, recommendations from the Severe Brain Injury to Neurological Determination of Death (SBINDD) Forum have been adopted by numerous professional organizations such as Canadian Critical Care Society and the Canadian Critical Care Nurses. In the case of Trillium Gift of Life in Ontario the recommendations were not only adopted but were incorporated into policy.

Public Awareness and Social Marketing Strategies

In an effort to provide the CDM with advice on moving those in support of donation towards committing to donation, the CCDT has been engaged in numerous activities related to public awareness and social marketing strategies. In previous years, the CCDT conducted an environmental scan, prepared a discussion paper and hosted two stakeholder consultations.

In 2004, the CCDT consolidated information and findings in the final phases of this initiative. Once again, stakeholders came together to review and make final recommendations which informed the resulting report entitled, Social Marketing Framework to Promote Organ and Tissue Donation in Canada. The report examined components including: key audiences, key messages, messengers, channels, partners, other strategic initiatives, time and resource commitments and evaluation. Other factors such as cost analysis, public surveys, and opportunities for collaboration in the areas of family recognition, family support and national organ and tissue donation awareness week were also considerations in formulating CCDT advice.

Ethnocultural and Religious Communities

Ethnocultural and religious communities have unique perspectives on organ and tissue donation. The CCDT seeks to gain an understanding of these unique perspectives which will be used to create advice for donation awareness and social marketing programs which are sensitive to ethnocultural diversity. The CCDT's exploration of the related challenges and opportunities has resulted in numerous key achievements. First, a comprehensive literature review was summarized in the report entitled A Summary of the Attitudes, Beliefs, and Values about Organ Donation of a Variety of Ethnocultural Communities. Second, a stakeholder consultation resulted in the plan for a community development consultation focused on capacity building and partnering with-in donation programs. The report entitled, Consultation on the CCDT Diverse Communities Initiative outlined consultations that will result in:

- Practical advice to the CDM on public policy that will support culturally appropriate awareness messages and donation/transplantation services.
- A model for engagement with ethnocultural and Aboriginal communities that could be applied in locations across Canada, taking into consideration local circumstances.
- Assessment of the capacity and interest within the communities for ongoing organ donation advocacy and partnership with local donation and transplant programs.

Medical Management to Optimize Donor Organ Potential

In the donation process there is an interval of care that begins with neurological determination of death and consent to organ donation and ends with surgical organ procurement. During this period, there is significant opportunity for enhancing multi-organ function and improving organ utilization.

In February 2004, a large group of health professionals in the critical care and transplantation fields gathered in Mont Tremblant, Quebec for the Medical Management to Optimize Donor Organ Potential Forum. Discussions focused on collaborative, consensus-based decision making to: develop a mechanism that bridges the critical care and transplant communities; review and benchmark existing (national and international) practices, guidelines and policies related to donor organ management; develop expert consensus for organ protective therapies for the ICU and interoperative management of the organ donor; and to develop recommendations for future research in this evolving field.

Forum deliberations were combined with numerous background documents, literature reviews and surveys into a final report and advice to the CDM.

The following documents developed by the CCDT provided background information for advice to the CDM:

- Steering Committee. (2004). Report on Medical Management to Optimize Donor Organ Potential: A Canadian Forum.
- Kutsogiannis DJ, Shemie SD, Doig C et al. (2004). Donor Organ Management: Literature Review
- Hornby K, Shemie SD. (2004). Donor Organ Management: Survey of Guidelines and Eligibility Criteria
- Meggison H, Kanji S, Shemie SD. (2004). The Role of Thyroid Hormone in Donation, Transplantation and Cardiovascular Diseases.
- Badovinac K. (2004). Canadian Review of Organ Utilization.
- Hornby K, Ross H, Keshavjee S, Rao V, Shemi SD. (2004). A Canadian Investigation Regarding Factors contributing to Non-Utilization of Hearts and Lungs after Consent for Donation: An In-depth Multi-Centre Review for 2002.
- Report on Severe Brain Injury to Neurological Determination of Death-A Canadian Forum (Vancouver).

Transferring Knowledge regarding Best Practices for the Determination and Declaration of Brain Death

In 2004 the CCDT built on previous initiative work to develop health system and practitioner resources and guidelines regarding best practices for the determination and declaration of brain death. Based on consensus decisions from the 2003 forum on Severe Brain Injury to Neurological Determination of Death, the CCDT has supported knowledge transfer by:

- Developing a forum report that includes clinical practice recommendations.
- Distributing reports and conducting over 100 presentations, nationally and internationally, to numerous health organizations in the critical care and transplantation fields. Dissemination included critical information relative to the processes of care for harmonized practice ranging from the determination and declaration of neurological death to the medical management of donors leading to organ recovery.
- Preparing an account of forum proceedings, background documents, literature reviews and surveys for peer-reviewed journal publication. Following peer-review a total of 19 documents will form a special issue of a major Canadian journal publication.

"I truly believe that Canada will be the model for the world with regards to donor evaluation and management. The concept of having this [forum] under the direction of independent arbiters (i.e. intensivists) is wise and will no doubt be effective."

Bruce Rosengard, MD
University of Cambridge, UK
Medical Management to Optimize
Donor Organ Potential Forum Attendee

Sample Presentations to Health Care Organizations regarding Best Practices for the Neurological Determination of Death, and Donor Management and Allocation:

International presentations:

- Neurological Determination of Death and Organ Donation in Children. 3rd World Congress of Pediatric Intensive Care, Boston.
- Canadian Perspectives on Brain Death. IV International Symposium on Coma and Death. Havana.
- Severe Brain Injury to Neurological Determination of Death. Procurement Council, the American Association of Organ Procurement Organizations. AOPO, Chicago

National Presentation:

- The Intensivists Role in Brain Death and Organ Donation. University of Toronto Critical Care Medicine Residents Day, Toronto Critical Care Medicine Symposium
- The Coroners Role in Organ and Tissue Donation. Annual Meeting of the Chief Coroners and Medical Examiners of Canada, Iqaluit, NWT
- Du Traumatisme Cerebral a la Determination de la Mort Cerebrale: Nouvelle Normes Medicales Canadiennes. Forum professionnel sur le don d'organes et de tissus, la Fondation canadienne du rein. (Professional Forum on Organ and Tissue Donation, Quebec Branch, Quebec City.
- From Severe Brain Injury to Neurological Determination of Death to Organ Donation. Controversies, Challenges and Resolutions?. Alberta Society of Intensive Care Physicians, 16th Annual Meeting. Lake Louise.
- From Severe Brain Injury to Neurological Determination of Death to Organ Donation. An Update on Canadian Initiatives. Neurology Grand Rounds, Hospital for Sick Children, University of Toronto
- Neurological Determination of Death in Newborns, Infants and Children: New Canadian Standards. Child Neurology Day, Pediatric Brain Injury Annual Scientific Meeting of the Canadian Congress of Neurological Sciences, Calgary. Jan 20, 2004.

Live Organ Donation

One of the strategies to address the shortage of organs from deceased donors (the traditional source of organs for transplant) is the transplantation of organs (i.e. generally a single kidney or part of the liver) from live donors. To develop a better understanding of the issues around live organ donation, the CCDT completed an environmental scan of current policies, practices, perceived issues and barriers, and possible solutions related to live organ donation in Canada. A broad range of stakeholders were contacted including governments, programs, physicians, health professionals, not for profit organizations and live organ donors. The resulting report entitled Environmental Scan of Policies, Practices, Experiences, Issues, and Barriers Related to Live Organ Donation, indicated that:

- policies and practices vary widely across the country,
- there is inadequate public and professional awareness of live organ donation,
- donors face substantial financial burdens, and
- there is limited knowledge of the long term health effects of live organ donation.

The CCDT intends to use this information to guide the development of other projects around live organ donation to develop advice to the CDM on how best to improve this practice in Canada.

“The CCDT has been instrumental in fostering national collaboration on issues of donation and transplantation and provided a much needed leadership role. The success of their groundbreaking initiatives, such as the national forums on the neurological determination of death and donor management, has enhanced clinical practice in Canada.”

Corinne Weernick
President, Canadian Association of Transplantation
Medical Management to Optimize
Donor Organ Potential Forum Attendee

Reporting Standards for Donor Activities

An objective of the CCDT is to develop appropriate standards for reporting actual and retrospective provincial donor activities. While the donors per million population is the rate traditionally used, there is a strong need to express cadaveric organ donation rates using a more meaningful measurement. The CCDT is building on existing work² which computed organ donor indices on the basis of diagnosis as reported in the Hospital Morbidity Database (HMDB). The first report entitled Refining Estimates of Potential Cadaveric Organ and Tissue Donors from Patient Death Records in Hospitalization Databases is based on literature reviews and data construction and analysis. These reports will result in advice that will address consistency for reporting and will enhance and enable accountability and evaluation of donation. Issues such as the nomenclature, definitions, quality indicators, essential data elements, and linkages to existing standards will be explored further as the second phase of advice is developed.

Transplantation Data Sets

The need for data collection, management and utilization to improve patient outcomes is a growing trend in health care and transplantation in particular. As a first step towards addressing information requirements for transplantation, the CCDT worked with the Canadian Institute of Health Information (CIHI) and the Canadian Organ Replacement Registry (CORR) to identify data requirements for live organ donors, and recipients assessed for organ transplantation to support improved transplantation outcome measurement. Results from the report titled, Minimal Data Set for A National Living Donor Registry, Patients Assessed for Transplantation & Expanded Transplant Recipient Outcomes: Final Report, are being used by the CCDT in developing and supporting current work plan initiatives related to donation and transplantation information requirements and management.

Select Findings from an "Environmental Scan of Policies, Practices, Experiences, Issues, and Barriers Related to Live Organ Donation

- Seventy-two percent of donors responding to the survey reported that their health was not being followed on a regular basis by a transplant/organ specialist.
- Only twenty-five percent of donation and transplant programs reported undertaking and performing long-term follow-up with live organ donors.

These findings highlight the importance of other CCDT initiatives in addressing information management surrounding donation and transplantation.

Tissue Banking and Transplantation

Progress on initiatives in the area of tissue banking and transplantation was temporarily suspended by the CDM during the external review of the CCDT. However, upon approving the proposed work plan in June 2004, the CDM identified work related to tissue banking and transplantation as a high priority. As a result, the CCDT is currently engaged in numerous initiatives that will result in advice regarding a tissue banking and transplantation model for Canada. Initial deliverables are expected next year.

Despite the delay in activities, previous work related to tissue banking and transplantation has been well received. For example, Health Canada, has utilized the findings from the 2003 CCDT investigation into the supply and demand of human allograft tissue in Canada as a resource in the development of the Regulatory Framework for Cells, Tissues and Organs Intended for Transplantation and as a resource for various departmental reports.

²Estimating Potential Cadaveric Organ Donors for Canada and its Provinces, 1992-1998: A Discussion Paper (2001), Canadian Institute of Health Information (CIHI).

Overview of the Canadian Council for Donation and Transplantation

Council

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

Ex-Officios

Ex-officio members serve as liaison between the CCDT and the government, region or organization they represent. Their role is to provide information to the Council on existing or planned policies and programs regarding donations 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 of Deputy Ministers of Health.

Standing Committees

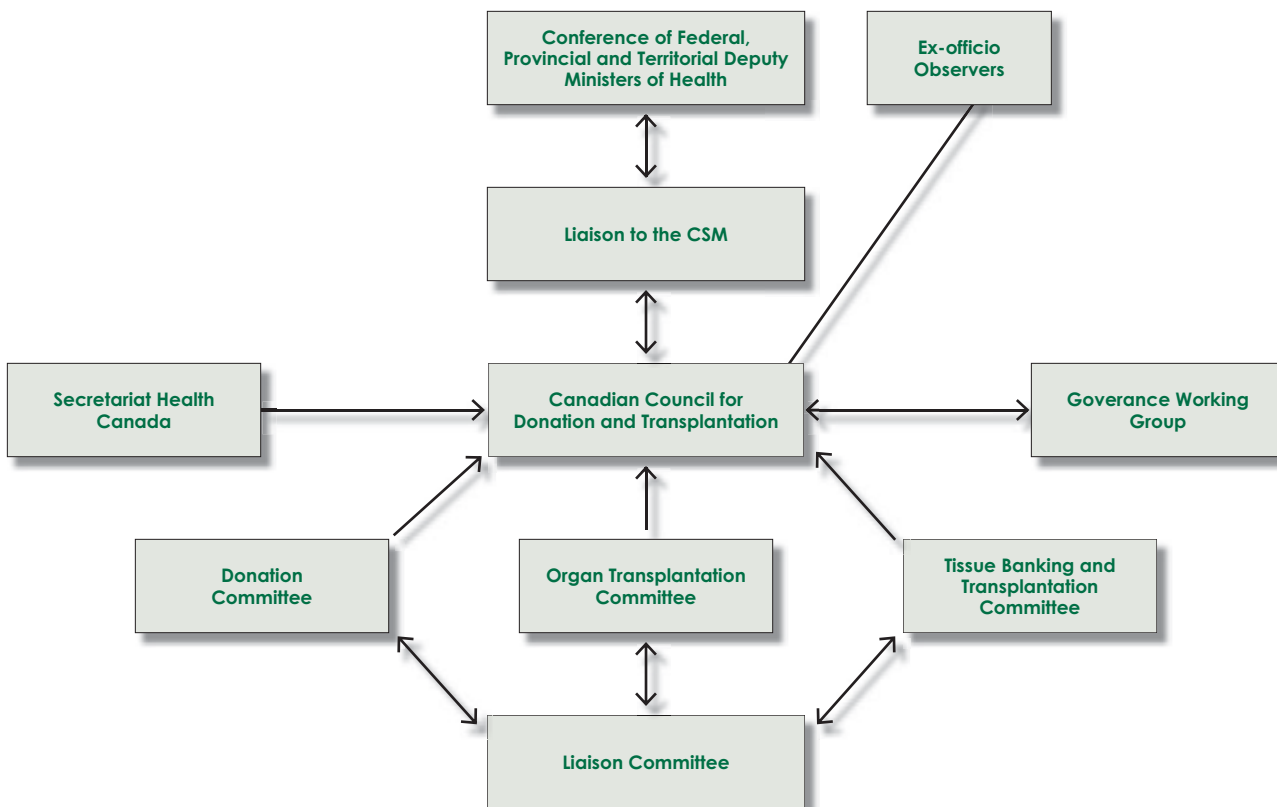
The Council utilizes a number of Standing Committees and Working Groups that include non-Council experts to augment expertise relative to the area of focus. The Standing Committees direct research and resource development in order to bring forward standards, policies and best practices for review and ratification by Council. Currently, there are four initiative-focused Standing Committees in the areas of Organ and Tissue Donation, Organ Transplantation, and Tissue Banking and Transplantation. The fourth Standing Committee, the Liaison Committee, facilitates cross-committee communication and directs collaboration on overarching initiatives such as ethical and legal issues. The Council also uses a Governance Working Committee, which supports internal processes related to leadership, review and revisions of governance documents and policy development.

CDM Liaison

As a representative of the Federal/ Provincial/ Territorial Conference of Deputy Ministers of Health, the CDM Liaison ensures effective communication and support between the CDM and the CCDT.

Secretariat

The Council and all its activities are supported by a Secretariat, which is responsible for the day-to-day administration of the CCDT. This includes financial and contract administration, coordination of meeting logistics, communication, evaluation and the provision of extensive project management support for the Standing Committees and Working Groups.



Council Members

Leah Hollins
(Council Chair, Liaison)
Victoria, British Columbia

Edward A. Ferre
(Tissue)
Vancouver, British Columbia

Sheilagh Ross
(Governance Lead)
Camrose, Alberta

Eugene Bereza, MD
(Tissue, Liaison, Ethics Lead)
Montreal, Québec

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

Graham Scoles, PhD
(Tissue)
Saskatoon, Saskatchewan

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

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

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

Diane S. Craig
(Donation)
Ottawa, Ontario

Michele Lahey
(Donation)
Edmonton, Alberta

Rosalie Starzomski, PhD
(Donation)
Vancouver, British Columbia

Christopher J. Doig, MD
(Donation, Liaison)
Calgary, Alberta

Vivian McAllister, MD
(Organ Transplantation)
London, Ontario

John B. Dossetor, MD
(Organ Transplantation)
Ottawa, Ontario

James William Mohr, MD
(Tissue, Liaison)
Halifax, Nova Scotia



From left to right in front row: John B. Dossetor, Michele Lahey, Rosalie Starzomski, Leah Hollins (Council Chair), Sheilagh Ross, Christopher J. Doig.

In the second row : Vivian McAlister, Sam D. Shemie, Graham Scoles, James William Mohr, David Hollomby, Eugene Bereza, Marc Germain, Rabbi Reuven P. Bulka.

Missing: Diane S. Craig; Edward A. Ferre.

Non-Council Committee Members

Max Bishop
(Donation)
St. John's, Newfoundland

Paul Byrne, MD
(Donation)
Edmonton, Alberta

Fides Coloma
(Tissue)
Toronto, Ontario

Raffaele Forcione
(Donation)
Montreal, Québec

Diane Hebert, MD
(Organ Transplantation)
Toronto, Ontario

Jonathan Lakey, PhD
(Tissue)
Edmonton, Alberta

Robert D. Levy, MD
(Organ Transplantation)
Vancouver, British Columbia

Ted Meeking
(Organ Transplantation)
Toronto, Ontario

Katrin Nakashima
(Organ Transplantation)
Westmount, Québec

Ex-Officio Members

Liz Anne Gilham-Eisen
Health Canada

Ann Secord
Atlantic Canada

Annie Robitaille
Quebec

Peter Biasucci
Ontario

Wayne McKendrick
Alberta, Saskatchewan, Manitoba,
Nunavut, Northwest Territories

Bill Barrable
British Columbia, Yukon

Paul J. Dubord, MD
Canadian Standards Association

Craig Knight
Liaison to the CDM

Financial Summary

Fiscal Year	2003-2004		2004-2005
	Budget	Actual	Estimate
Budget Allocation	\$3,818,000	\$3,818,000	\$3,818,000
Distribution of Funds			
Council	\$659,000	\$369,256	\$659,000
Secretariat	\$500,000	\$508,603	\$500,000
Initiatives	\$950,000	\$897,298	\$2,217,000
Total Expenditures	\$2,109,000	\$1,775,157	\$3,376,000
Surplus/(Deficit)	\$1,709,000	\$2,042,843	\$442,000