

A large, thick green ribbon graphic that forms a large, stylized number '9' or a similar shape, dominating the left and center of the page. It starts at the top left, curves around to form a large loop, and then extends downwards and to the right, ending in a tail that tapers off.

^{2 0 0 5}
Annual
REPORT



CANADIAN COUNCIL FOR
DONATION AND TRANSPLANTATION

CONSEIL CANADIEN POUR
LE DON ET LA TRANSPLANTATION

TABLE OF *Contents*

- 01. Message from the Chair
- 02. Message from the Chief Executive Officer
- 04. Highlights of the Past Year
- 05. Partners and Stakeholders
- 07. Overview of the Mandate and Initiative Process
- 09. Donation Initiatives:
 Message from the Chair of the Committee
- 10. Organ Transplantation Initiatives:
 Message from the Chair of the Committee
- 11. Tissue Banking and Transplantation Initiatives:
 Message from the Chair of the Committee
- 12. Initiative Achievements in the Past Year
- 16. Financial Summary

© 2005 The Canadian Council for Donation and Transplantation

This report may be reproduced in its present format without permission. Any alteration of contents must be approved by the Canadian Council for Donation and Transplantation.

For reprints, please contact: **The Canadian Council for Donation and Transplantation**
1702, 8215 112 Street | Edmonton, AB, Canada T6G 2C8 | www.ccdt.ca | 780 409-5651 | info@ccdt.ca

The views expressed herein do not necessarily represent the views of the Canadian Council for Donation and Transplantation and/or the Federal, Provincial or Territorial governments of Canada.

Production of this advice/report has been made possible through a financial contribution from Health Canada.





MESSAGE FROM THE *Chair*

In 2005, the CCDT became a non-profit organization after four years under the direction of Health Canada. We successfully navigated the many changes that this re-organization entailed and positioned ourselves for new opportunities.

Not only did the CCDT Council embrace this year of transition with enthusiasm and foresight, they clearly focused on the achievement of an ambitious work plan. A number of consensus-building meetings were held and key reports completed which contributed to the improvement of the organ and tissue donation system in Canada.

Throughout this transition, we took steps to strengthen our governance. The Council By-Laws were revised, governing roles and responsibilities were approved and an Executive Committee was established.

I am pleased to welcome five new members to Council. Dr. Jonathan Lakey, of Edmonton, Alberta, brings expertise in tissue banking and transplantation.

Dr. Charles Sun, Victoria, British Columbia, brings experience as an emergency physician and provides linkages with paramedics. Dr. Vinay Dhingra, Vancouver, British Columbia, represents critical care which is a new stakeholder addition to the Council. Dr. Frank Markel, of Toronto, Ontario, the CEO of an organ procurement organization and previously an Ex-Officio Representative on the Council, will take a seat as a Council Member. Dr Peter Nickerson, Winnipeg, Manitoba, a nephrologist and transplant specialist, has also been added to Council as a Member-at-Large.

As the Chair of the Council, I invite you to review our 2005 Annual Report to learn more about the exciting and challenging year of transition for the CCDT. Finally, and most importantly, I thank the Volunteers and Staff of the CCDT for an extremely successful year.

Leah Hollins
Chair of the Council of the CCDT
November 2005

MESSAGE FROM THE *CEO*



Our most significant achievement this year was the CCDT transition from a Health Canada secretariat to an arms-length, non-profit organization. Throughout this transition, our mandate to provide advice directly to the Conference Deputy Ministers of Health (CDM), related to a coordinated strategy for improving donation and transplantation in Canada, remained unchanged.

Our transition provided us with a new beginning that brought with it the opportunity to focus on new ways of achieving our goals. We remain committed to our board's priorities, to partnerships and collaboration, to excellent communication, to management effectiveness and to performance measurement and evaluation.

To ensure the CCDT Council's strategic priorities are realized, we will work in collaboration with governments, organ and tissue donor organizations, hospital programs, professional organizations, non-profit organizations and recipients, donors and their families. We will be responsive to changing situations

and proactive in recognizing new opportunities for partnerships to develop.

We now have a number of completed projects and we are changing our focus to facilitate knowledge transfer. With support from the CDM, we intend to communicate our reports widely and, as the first step toward this goal, our website became operational in May 2005. As well, we will have a number of publications in peer-reviewed journals this year.

Ultimately, as a new organization, we are focused on management effectiveness and accountability, which includes measuring how well the CCDT staff actualizes Council plans; how management utilizes financial and human resources to achieve results; and how positively the organization is perceived, as practices gain stability and predictability.

We appreciate and value your support and commitment as our organization moves forward.

A handwritten signature in cursive script that reads "Kimberly Young".

Kimberly Young
Chief Executive Officer of the CCDT

great need

In a 2005 survey by Environics on behalf of the CCDT, it was found that 80% of Canadians believe there is a *great need* for more organ donations.



HIGHLIGHTS OF THE *Past Year*

The CCDT in Transition

While the CCDT was in transition from a Secretariat of Health Canada to an arms-length, non-profit organization, numerous changes were realized in the organization. The Council and Staff of the CCDT made significant strides towards increasing the effectiveness of the organization while managing the growth of the organization.

Contracts with consultants were limited as staff was increased to deliver on an ambitious work plan. The first Annual General Meeting of the new organization was held in September of 2005 in Halifax. The Canadian public had access to the work of the CCDT through www.ccdt.ca as of May 2005.

Advice from the 2005 Work Plan

Many reports and background documents were produced by the CCDT in 2005 as a result of stakeholder meetings, including those with recommendations about improving specific aspects of the clinical practices in the Canadian donation and transplantation system.

The CCDT presented the following advice in 2005 to the Federal/Provincial/Territorial Conference of Deputy Ministers of Health:

- Assessment and Management of Immunologic Risk in Transplantation.
- Medical Management to Optimize Donor Organ Potential.
- Donation after Cardiocirculatory Death.
- Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation.
- Public Awareness Strategies.

PARTNERS AND *Stakeholders*

The mandate of the CCDT is to provide advice to the Federal, Provincial and Territorial Conference of the Deputy Ministers of Health (CDM) in order to improve organ and tissue donation and transplantation in Canada. We base that advice on literature reviews, on existing clinical practices and guidelines for best practices developed by stakeholder groups, and on recommendations developed through consensus at the national fora hosted by the CCDT.

To develop this advice, we partner with 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. These stakeholders commit thousands of hours toward the realization of CCDT initiatives which informs the advice that the CCDT offers to the CDM.

Canadian Anesthesiologists' Society
Canadian Association of Critical Care Nurses
Canadian Association of Emergency Physicians
Canadian Association of Neurology 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 for Health Information
Canadian Organ Replacement Registry
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
Critical Care Facilities
Eye and Tissue Banks
Federal Government Departments,
particularly Health Canada
Heart and Stroke Foundation of Canada
International Society for Heart and
Lung Transplantation
Kidney Foundation of Canada
National Emergency Nurses Affiliation
Operating Room Nurses Association of Canada
Organ Procurement Organizations
Provincial and Regional Health Authorities
Provincial Government Departments,
particularly Provincial Health Ministries
Quebec Society of Intensivists
Transplant Hospitals and Transplant Programs
Trauma Association of Canada
Trauma Coordinators of Canada
United Network for Organ Sharing

family
Fifty-eight percent of Canadians have *talked to*
their families about organ and tissue donation.
awareness



OVERVIEW OF THE *Mandate* AND INITIATIVE DEVELOPMENT PROCESS

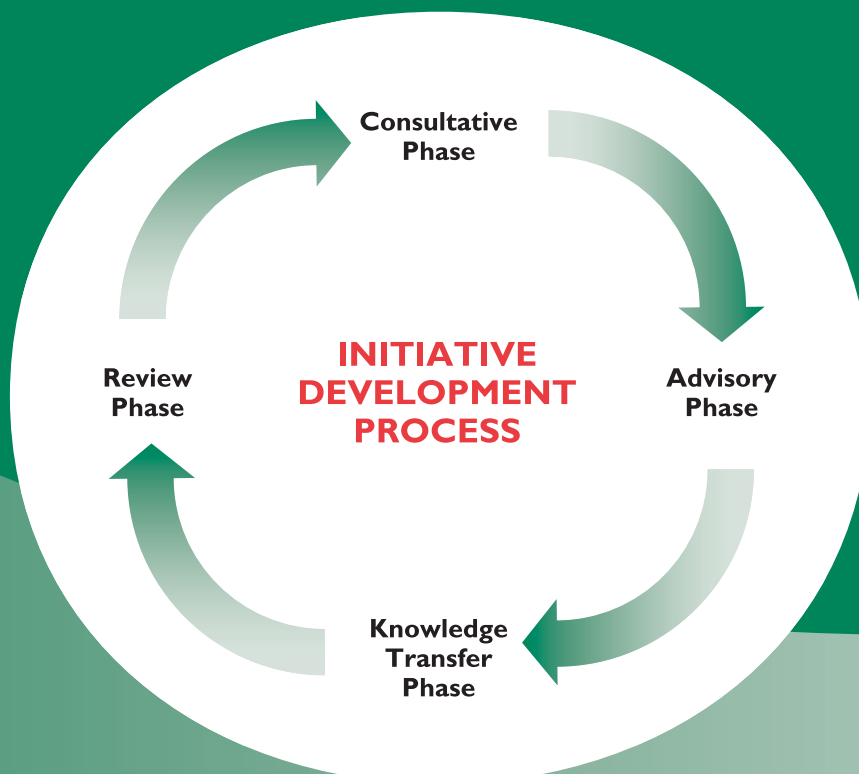
Through work based on its mandate, the CCDT develops and provides advice about improving organ and tissue donation and transplantation for the Federal/Provincial/Territorial Conference of Deputy Ministers of Health (CDM). The Council and Staff of the CCDT work closely to develop that advice through a work plan that identifies key initiatives.

Phases of an Initiative

The consultative phase involves engaging key stakeholders, defining the issues and refining questions, doing background research, and

formulating by consensus various recommendations about best practices in organ and tissue donation and transplantation. The advisory phase commences with the presentation of the final initiative report to the CCDT Committee responsible for the initiative and to the CCDT Council. Advice based on the report is then generated for the CDM.

The knowledge transfer phase includes publishing and distribution of the final report, presentations and publications in professional journals. The review phase involves incorporating stakeholder feedback into the review and refinement of recommendations in the report. It also involves tracking of implementation of recommendations.



decision to donate

Ninety-one percent of Canadians are very confident or somewhat confident that *their views and intentions in regards to organ and tissue donation will be respected.*





Donation Initiatives

MESSAGE FROM THE CHAIR OF THE COMMITTEE

I want to take this opportunity to congratulate and thank the outgoing Chair, Dr. Chip Doig, for his leadership of the Donation Committee from 2002 to 2005. I was pleased to accept the role of Chair in June 2005.

Our committee continues to focus on engaging the public and health care professionals to optimize end-of-life care and address the shortage of organs and tissues in several ways.

Engaging the public, we completed consultations during which we heard the perspectives of people from South Asian, Chinese and Aboriginal communities in selected sites across Canada. We also held a public consultation with religious communities. We completed several public surveys and produced a practical guide for organizations to develop their own public awareness activities.

Collaborating with health care professionals from across Canada, we focused on developing innovations in donor care in emergency departments, intensive care units and operating rooms. These include:

- National guidelines for neurological determination of death.
- Maximizing donor identification.
- Addressing deficits in organ utilization from existing donors through state of the art donor management.
- Establishing the medical/ethical/legal framework for the development of donation after cardiocirculatory death programs.

We have a significant number of initiatives in the early stages of development including:

- Health professional education.
- Donation prior to hospital admission.
- Reporting on donation potential from existing statistical data.

We continue to strive to support excellence in care and to engage the public. I look forward to working with Donation Committee members, in partnership with health care professionals and the public, to address deficits in end-of-life care and in turn, help those in need of transplants.

Dr. Sam Shemie
Chair of the Donation Committee

Organ Transplantation Initiatives



MESSAGE FROM THE CHAIR OF THE COMMITTEE

The Organ Transplantation Committee focused this year on several initiatives that will enhance transplantation in Canada. Our Committee's strategy is to develop a framework for action at local, provincial, territorial and national levels which will result in a sustained, systematic approach to safe and ethical organ transplantation across our country.

The Committee established a work plan to address several challenging and principal components of organ transplantation, such as:

- Optimally supporting and referring potential transplant recipients.
- Assessing and listing patients waiting for transplants on common and transparent criteria.
- Exploring opportunities and challenges of live organ donation.
- Optimally monitoring and evaluating transplant recipients.
- Optimizing organ utilization and allocation.

I continue to look forward to working with Committee members in partnership with health care professionals from across Canada to support excellence in transplant care.

A handwritten signature in cursive script, appearing to read "D. Hollomby".

Dr. David Hollomby
Chair of the Organ Transplantation Committee



Tissue Banking and Transplantation Initiatives

MESSAGE FROM THE CHAIR OF THE COMMITTEE

The Tissue Banking and Transplantation Committee continue to be concerned over the variability in access for Canadians to tissue banking services. The past year has seen a great deal of progress in identifying issues which contribute to the availability of specific products and inventory shortfalls. Equity in access to safe tissue has been a driving force in our work.

The Tissue Banking Committee has identified impediments to the cohesive delivery of tissue banking services in Canada. Each step in the continuum from tissue donation to tissue distribution is a key to the identification of obstacles and opportunities for improvement. The CCDT will use this work to provide comprehensive recommendations regarding structure and possible interoperability for Canadian tissue banks.

I would like to acknowledge the Canadian tissue communities, from surgeons to donation groups, to

tissue banks to Health Canada. These communities have come together to support CCDT tissue initiatives during my tenure as Chair. I am confident the CCDT will continue to build on their initiatives with a forum of these communities which will make recommendations to support Canada in leading the world in innovation and practice in tissue systems. I am honoured to have had the opportunity to collaborate with the CCDT and work with these amazing communities from across our country.

The Committee has enhanced its' membership to ensure that further work will consider technological advancements and ensure views of all stakeholders are represented. Finally, I welcome Dr. Marc Germain as the incoming Chair of the Committee and I thank all members for their commitment over the past year.

Jim Mohr
Chair (Outgoing) of the Tissue Banking
and Transplantation Committee

INITIATIVE ACHIEVEMENTS IN THE *Past Year*

Canada is unique in North America in favouring a society that is a multi-cultural mosaic, rather than a melting pot. In light of the growing diversity of Canadian society, the CCDT endeavours to support diverse ethnocultural and Aboriginal communities to understand their perspectives and to provide recommendations for donation and transplant organizations to consider for improving donation rates.

Our 2005 publication, *Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation Summary Report*, outlines what we learned about the perspectives of these communities on donation and transplantation, and summarizes ways of consulting with diverse groups. Consultations with diverse communities facilitate personal considerations about the possibility of donation.

The CCDT recognizes that the decision to donate organs and tissues involves more than medical considerations. As noted in our 2005 report, *The Inter-Faith Forum on Organ and Tissue Donation and Transplantation*, no major faith organization in Canada is opposed to organ and tissue donation and transplantation. The CCDT continues to collaborate with faith groups to bring greater understanding to this issue.



Nearly all of Canadians have *heard* about organ and tissue donation (93%).

In our focus on improving hospital practices, we find that the input of the public and health service providers is essential to an effective system of donation and transplantation activities in Canada. In 2005, the CCDT conducted national surveys of the Canadian public and health care professionals about organ and tissue donation. The surveys solicited opinions regarding personal views on organ and tissue donation and donation after cardiocirculatory death. Public opinion endorsed the consensus agreement reached by the health care professionals.

Public opinion polls have consistently shown Canadians support organ and tissue donation, yet this support has not translated into increased donation. Ongoing awareness and education is vital to enable Canadians to make informed choices and increase participation in donation. *Guide for Planning and Budgeting Public Awareness and Education Initiatives to Promote Organ and Tissue Donation* was produced in 2005 to further these aims. We know that more people are talking to their families about their wishes for donation; our reports provide suggestions to implement ongoing awareness.

A study of various components of tissue banking in Canada is underway. This process will illuminate current practice and offer potential opportunities for tissue banking in the future. The CCDT review of the supply of human allograft tissue in Canada

indicated a large amount of unknown source allograft bone tissue being used by Canadian hospitals. One source of this tissue is surgical bone banks. Our report, *Evaluation of Surgical Bone Banking and Utilization in Canada*, identifies the potential for surgical bone banking in Canada and identifies ways to enhance the process from collection to distribution.

The CCDT convened a meeting of clinical and laboratory specialists in 2005 with a focus to improve access to transplantation. The intent of the meeting was to improve solid organ transplant outcomes, improve equity of access to organ transplants for highly sensitized patients, reduce the wait-list time for highly sensitized patients, and increase the number of donors. One outcome of the meeting was our publication, *Assessment and Management of Immunologic Risk in Transplantation: A CCDT Consensus Forum*.

CCDT published the report, *Donation after Cardiocirculatory Death: A Canadian Forum: Report and Recommendations*, also as the result of another national, multidisciplinary consensus forum held in 2005. The purpose of the forum was to discuss and develop recommendations on the principles, procedures and practices related to donation after cardiocirculatory death, within a sound ethical and legal framework and in the context of protecting and serving the public. Many programs across the country are using this information as they consider implementing a donation after cardiocirculatory death program in their hospitals.

THE CCDT *Team*

THE CCDT COUNCIL FOR 2005



Front (L to R): Michele Lahey, Jim Mohr, Dr. Graham Scoles, Rabbi Dr. Reuven Bulka

Back (L to R): Dr. John Dossetor, Diane Craig, Dr. Vivian McAlister, Dr. Rosalie Starzomski, Leah Hollins, Dr. David Hollomby, Dr. Marc Germain

Missing: Dr. Sam Shemie

THE CCDT STAFF AT 2005 AGM



Front (L to R): Beverley Curtis, Tracy Brand, Kimberly Young

Back (L to R): Elisabeth Almeida, January Galiwoda, Christina Rogers, Carole Loiseau

RESPECT FOR CANADIAN *Diversity*

During 2005, the CCDT met with diverse ethnocultural and religious communities to explore their perspectives on organ and tissue donation with the intent to develop a framework for providing information on donation in a meaningful way for all Canadians.

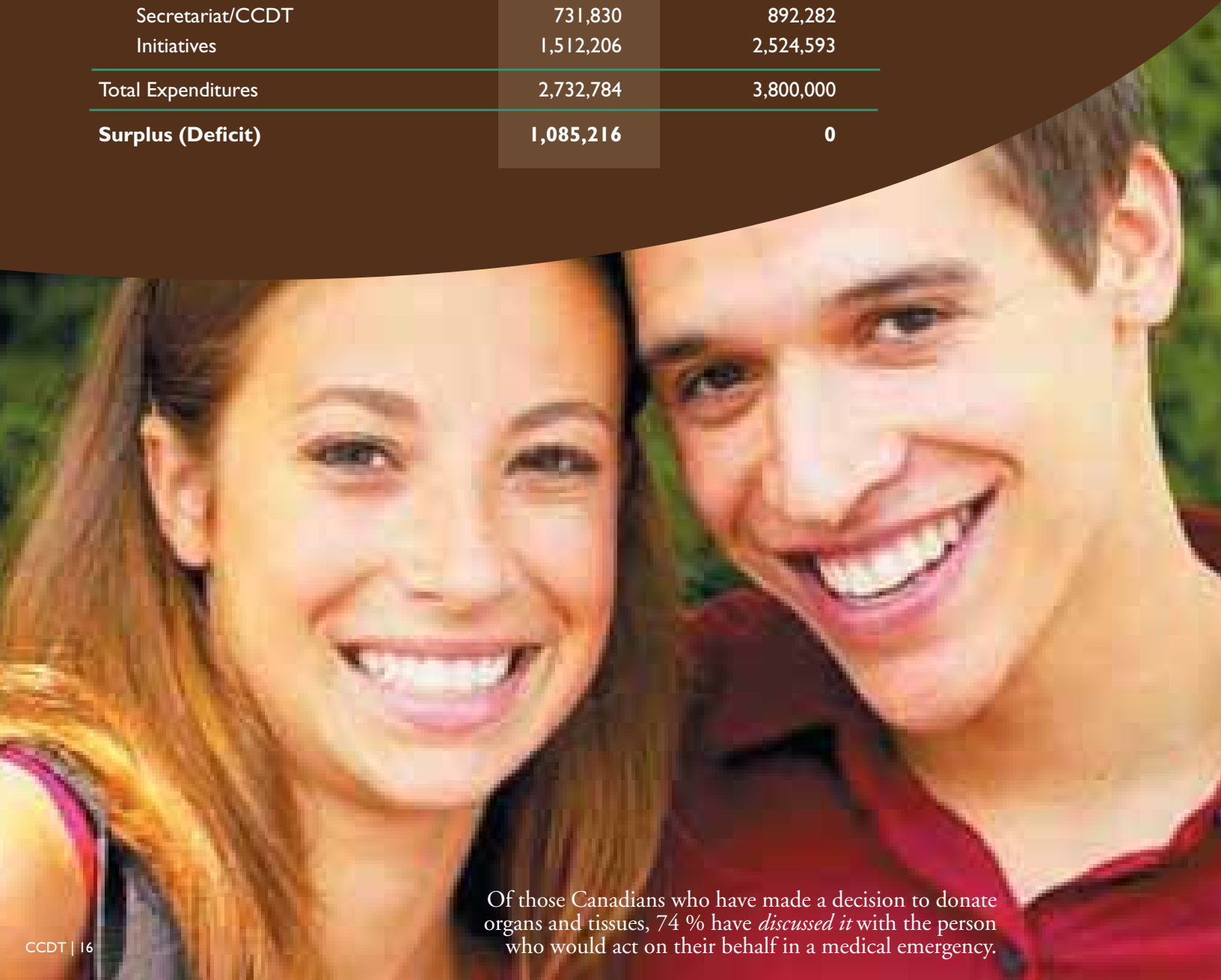
The 2005 Environics survey commissioned by the CCDT supported the importance of consulting with these communities. The top 3 reasons for deciding not to donate organs and tissues were: 1) Have a medical condition, can't donate; 2) Religious/spiritual beliefs; and 3) Personal preference/beliefs/just don't want to.



FINANCIAL *Summary*

As the CCDT is a newly formed not-for-profit organization with an initial fiscal year end of March 31, 2006, there are no Audited Financial Statements to present. The following financial summary is being presented based on the Health Canada Model.

Fiscal Year	2004-2005 Actual	2005-2006 Estimate
Budget Allocation	3,818,000	3,800,000
Distribution of Funds		
Council	488,748	383,125
Secretariat/CCDT	731,830	892,282
Initiatives	1,512,206	2,524,593
Total Expenditures	2,732,784	3,800,000
Surplus (Deficit)	1,085,216	0



Of those Canadians who have made a decision to donate organs and tissues, 74 % have *discussed it* with the person who would act on their behalf in a medical emergency.