REPORT OF THE
ORGAN AND TISSUE TRANSPLANTATION
WAIT TIMES EXPERT PANEL

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Expert Panel Chair

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CONTENTS

EXECUTIVE SUMMARY

Solid organ transplantation is a very successful life saving treatment for people with end-stage organ failure. Not only does transplantation significantly increase people's chances of long-term survival and improve their quality of life, transplantation is cost-effective. Unfortunately, if a person in Ontario needs an organ transplant today, there is a very good chance that he or she will wait a long time with about 1,700 other people or die before an organ becomes available. On May 27, 2009, 1,680 people were waiting for an organ transplant in Ontario. People waited an average of five years for a kidney but depending on the wait list at each hospital, it could have been 2.5 to seven years. Every three days, someone on the organ transplant waiting list dies. Some believe that this underestimates the crisis situation since people who might benefit from an organ transplant may not be put on a transplant wait list. For example, only 13% of people on dialysis in Ontario are on a kidney transplant wait list. Generally, access to a tissue transplant is more timely in most areas (except for cornea) although costly: Ontario meets less than 8% of the provincial demand for tissue and pays out about $19 million a year to buy tissue from out-of-province tissue banks.

Transplantation	
Organs	***Tissues***
• Heart • Kidney • Liver • Lung • Pancreas • Small Intestine	• Bone • Cardiovascular (heart valves, veins) • Connective (tendons, ligaments) • Cornea • Skin

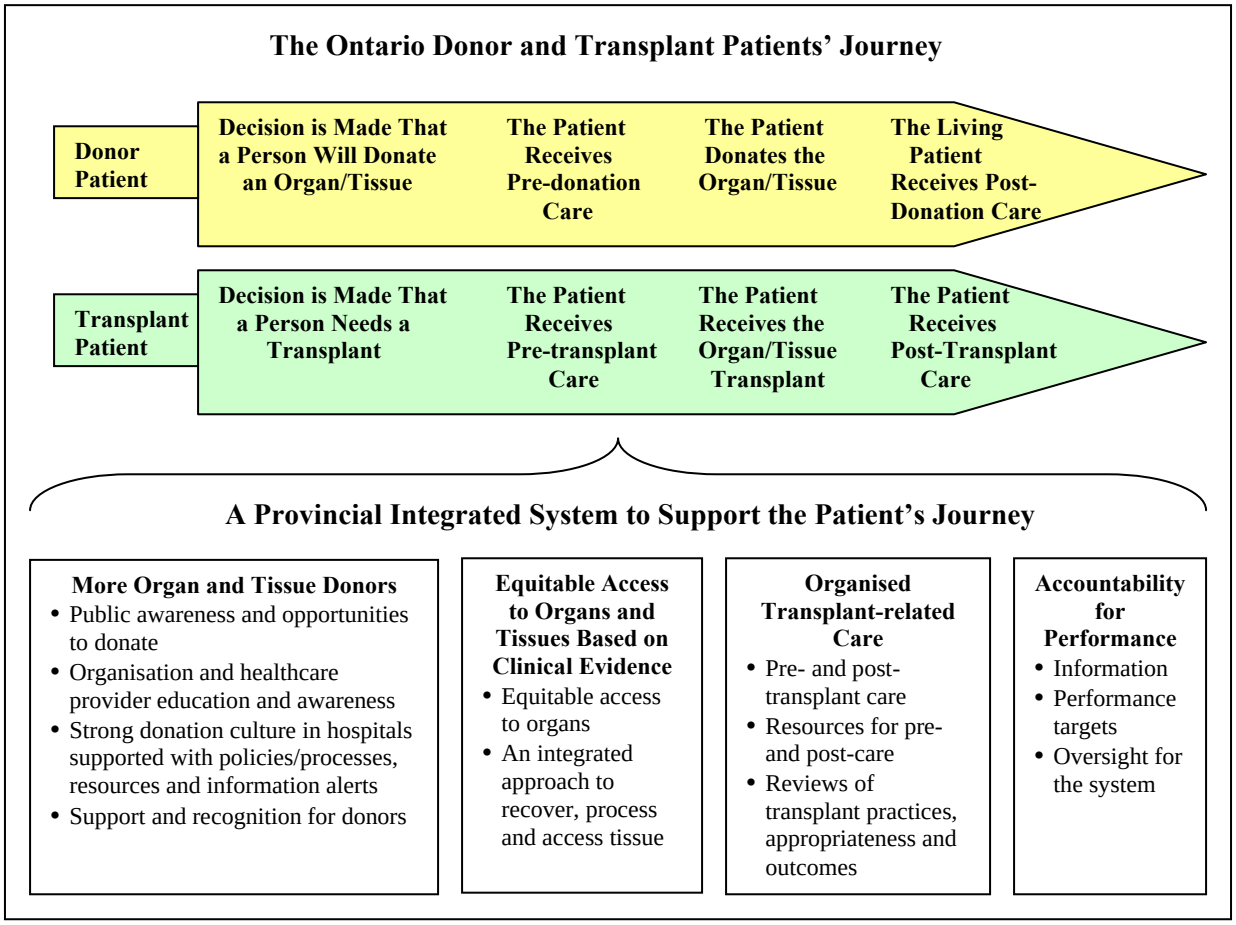
There is a shortage of organ and tissue donations in Ontario despite fairly significant investments of time and energy in the donation and transplantation systems. These include but are not limited to Trillium Gift of Life Network – an Ontario Government agency focused on organ and tissue donation – and seven hospitals that perform organ transplants on eight sites. Although the number of organ donations has increased in Ontario since 2000 – largely due to the increase in living donors – the *donation rate* has remained steady. In fact, Ontario's deceased donation rate per million population is below the Canadian average and below many other jurisdictions. The fact remains: wait times for transplantation will continue to be long unless there are more organ donors.

In November 2008, the Ministry of Health and Long-Term Care (Ministry) established the Organ and Tissue Transplantation Wait Times Expert Panel under the leadership of Dr. Gary Levy (Director, Multi-Organ Transplant Program; Director, University of Toronto Transplantation Institute; CIHR/Novartis Chair in Transplantation, University Health Network). The Panel – which reflects a broad range of experience and expertise – was asked to advise the Ministry on a plan to provide Ontarians with equitable access to timely, appropriate and safe organ and tissue transplants. The Panel is advising the Minister of Health and Long-Term Care, through Dr. Alan Hudson, Provincial Lead, Access to Services and Wait Times.

The Panel reviewed numerous published reports and documents on transplantation and related issues, analysed data, deliberated in working groups, and benefited from a one-day transplant symposium held on May 4, 2009: *Increasing Access and Reducing Wait Times for Transplantation in Ontario: the Path Forward.*

THE PANEL'S DELIBERATIONS AND RECOMMENDATIONS

The Panel focused its deliberations on the system that needs to be in place to support the donor and transplant patients' journey. There are four main components that must work together effectively if Ontarians are to have equitable access to timely, appropriate and safe organ and tissue transplants.



Component One: More Organ and Tissue Donors

For Ontarians to expect that an organ or tissue will be available if they need it, comprehensive and sustained efforts must be made to get more organ and tissue donors. As one Panel member noted, "transplantation equals donation."

Public Awareness and Opportunities to Donate: The Panel recommends that Trillium collaborate with the donation and transplantation communities to develop a strategic marketing and education plan to increase public awareness of donation and transplantation, and build a donation culture where Ontarians believe that organ donation is part of the cultural fabric of this province. A epidemiological study of donor

characteristics that impact on supporting living and deceased donation should inform this work. The Panel also recommends that Ontarians be able to register their desire to donate online.

Organisation and healthcare provider education and awareness: The Panel recommends that Trillium collaborate with the donation and transplantation communities to develop an organisation and healthcare provider awareness and education plan about donation. The plan should incorporate innovative ways to promote awareness such as programs that can be used as continuing education credits for recertification with regulatory colleges.

Strong donation culture in hospitals supported with policies/processes, resources and information alerts: The Panel makes a number of recommendations to develop strong donation cultures. Hospitals with Level 3 critical care units should identify a donation champion, establish an Organ and Tissue Donation Committee, and notify Trillium *after* the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies and *before* the withdrawal of these therapies has begun. These hospitals should also adopt standard policies for donation after neurological or cardiocirculatory death.

Other recommendations to build strong donation cultures include requiring Ontario's Critical Care Secretariat, the Neurosurgery Expert Panel, and the Emergency Room/Alternate Level of Care Expert Panel to integrate donation as part of end-of-life care in their respective strategic areas; for the Critical Care and Emergency Room Leads in each Local Health Integration Network to promote and support donation in their LHINs; for the Ministry to continue funding the donor coordinator program and tissue donor consent and screening; for the Ministry's Critical Care Secretariat to assess the critical care bed supply to support donation and to work with Trillium and the Neurosurgery Expert Panel to ensure that current and proposed information systems can be used as tools to alert Trillium about the potential for donation. In particular, neurosurgeons who are viewing the Emergency Neurosurgery Image Transfer System should be required to contact Trillium when potential donation opportunities arise. Finally, the Panel recommends that the Ministry review the payment schedule for donation and transplantation and physician compensation within the current Ontario Medical Association funding envelope so that financial barriers are removed from donation and transplantation.

Support and Recognition for Donors**:** The Panel recommends that the Program for Reimbursing Expenses of Living Organ Donors be enhanced and that a provincial program be developed that recognises all deceased and living organ and tissue donors in Ontario.

Component Two: Equitable Access to Organs and Tissues Based on Clinical Evidence

Equitable access to organs: A concerted effort must be made to increase the number of deceased organ donors in the province, and reduce the disparities in the rate of deceased

organ donations across the regions. As part of Ontario's Wait Time Strategy, there must be equitable access to organs based on clinical evidence. The Panel recommends that Trillium and the transplantation community review the allocation and distribution of organs, and identify improvements so that Ontarians have equitable access to organ transplants based on clinical evidence.

The Panel also supports an ***integrated approach to recover, process and access tissue.*** It recommends that one coordinated tissue recovery system be developed for Ontario and managed by Trillium, and that a coordinated, not-for-profit tissue processing and accessing system be developed to meet the needs of Ontarians for tissue. The system should take a provincial consortium approach with several sites operating within a single management structure, and coordinate and integrate the efforts of the current tissue banks.

Component Three: Organised Transplant-Related Care

The Panel recommends that Ontario's transplantation community compile and/or develop ***pre- and post-care best practice standards and guidelines*** and that providers use these to inform their care. Innovative approaches should be used especially in local communities and with local providers. This is especially important in northern and rural areas. The Panel also recommends that a ***resource manual*** be developed for people waiting for an organ donation, and that ***physician compensation*** for pre- and post-transplant be addressed within the current funding envelope. Finally, a system needs to be developed to monitor the use of ***best practice standards and guidelines for adult and paediatric organ transplantation***, and the outcomes of these procedures. This should include a regular provincial case review process made up of organ-specific committees, external reviewers who audit cases, and discussions of appropriateness, outcomes and areas for improvement.

Component Four: Accountability for Performance

A key cornerstone of Ontario's Wait Time Strategy has been accountability for performance. Everyone involved in supporting the donor and transplant patients' journey must be held accountable for their performance. The Panel recommends that the Wait Time Information Program work with expert transplant clinicians to develop a ***consistent standard definition of wait time for an organ, and a provincial priority rating scale with target time frames*** for organ transplants. These wait times should be publicly reported on the provincial wait times website. In addition, the Panel recommends that ***performance indicators be identified and targets set*** for donation and transplantation that are linked to outcomes and accountabilities for performance. These targets should be included in accountability agreements.

The final requirement to achieve accountability for performance and, ultimately, create an integrated system to support the transplant patient's journey is ***oversight for the system***. It can be argued that system oversight is the most critical requirement for an effective and well-functioning provincial donation and transplant service. It became very clear over the course of this review that no one organisation is accountable for Ontario's

provincial donation and transplantation system. Indeed, at times it was difficult to decide to whom some of the Panel's recommendations should be directed. To help address this situation, the Panel recommends that the Ministry conduct a role review of Trillium and the transplant centres with the goal of determining the best structure to provide effective oversight for the system for donation and transplantation in Ontario.

SECTION A: INTRODUCTION

1. BACKGROUND

Solid organ transplantation is a very successful life saving treatment for people with end-stage organ failure. Transplantation significantly increases people's chances of long-term survival. Quality of life is excellent and patients can expect to return back to their lives and families. Transplantation is also cost-effective: it reduces the need for expensive medical treatments such as dialysis and repeated hospital admissions. Unfortunately, if a person in Ontario needs an organ transplant today, there is a very good chance that they will wait a long time with about 1,700 other people or die before an organ becomes available.

Transplantation	
Organs	***Tissues***
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On May 27, 2009, 1,680 people were waiting for an organ transplant in Ontario.[1] People waited an average of five years for a deceased donor kidney. Depending on which hospital wait list a person was on, the median wait varied from 2.5 to seven years – if the person survived.[2, 3] Every three days, someone on the organ transplant waiting list dies.[4] Some believe that this underestimates the crisis situation since people who might benefit from an organ transplant may not even be put on a transplant wait list. For example, only 13% of people on dialysis were on a kidney transplant wait list in Ontario.[5]

Access to a tissue transplant is better in some areas. Although one can expect to wait about a year and a half for a cornea transplant in Ontario, access to other tissues such as skin, bone, cardiovascular tissue and connective tissue is easier but costly. Ontario meets less than 8% of the provincial demand for tissue and pays out about $19 million a year to buy tissue from out-of-province tissue banks.[6]

There is a shortage of organ and tissue donations in Ontario despite fairly significant investments of time and energy in the donation and transplantation systems. These include but are not limited to the Trillium Gift of Life Network – an Ontario Government agency focused on organ and tissue donation – and seven hospitals that perform organ transplants (on eight sites). In 2000, Ontario developed a comprehensive plan and

[1] Trillium Gift of Life Network: www.giftoflife.on.ca. Accessed May 27, 2009.
[2] The median wait time is the point at which 50% of people have had their transplants.
[3] See Chapter 7, Tables 6 and 7.
[4] Frank Markel, President and CEO, Trillium Gift of Life Network, "Record Levels of Organ and Tissue Donations Reached in Ontario" Ministry of Health and Long-Term Care, *News Release*, February 7, 2007.
[5] See Chapter 7, Table 15.
[6] See Chapter 8, Figure 16.

strategy to double the province's organ donation rate from the years 2000 to 2005.[7] In 2004, it was recognised that this target could not be achieved. The *2004 Ontario Budget* set a new goal of an additional 425 organ transplants by the end of 2007/2008. This goal has not been achieved. (In 2004, Trillium reported 727 total organ transplants in Ontario; by the end of 2008, an additional 125 organ transplants were performed over this base number.[8]) Although the number of organ donations has increased, the donation rate – which takes into account the growth of Ontario's population – has remained steady from 1996 to the present. In fact, Ontario's donation rate per million population is below the Canadian average and below many other jurisdictions such as the United States and Spain. Within Ontario, donation rates vary by region of the province.

Ontario needs to have a provincial transplantation plan that takes an integrated approach to this highly specialised service. This is especially important given the challenges with access to and wait times for transplantation. These challenges are expected to increase with Ontario's aging population and the growth in chronic diseases. The provincial transplantation plan needs to include more organ and tissue donors, equitable access to organs and tissues based on clinical evidence, organised transplant-related care, and accountability for performance.

Many of the solutions to improve access to transplantation have been implemented in other clinical areas as part of Ontario's Wait Time Strategy (e.g., standard information, performance targets, accountabilities). Improving access to transplantation will build on these solutions and reduce the time that Ontarians wait for this critical service.

2. THE ORGAN AND TISSUE TRANSPLANTATION WAIT TIMES EXPERT PANEL

In November 2008, the Ministry of Health and Long-Term Care (Ministry) established the Organ and Tissue Transplantation Wait Times Expert Panel under the leadership of Dr. Gary Levy (Director, Multi-Organ Transplant Program; Director, University of Toronto Transplantation Institute; and CIHR/Novartis Chair in Transplantation, University Health Network). The members of the Expert Panel reflect a broad range of experience and expertise in organ and tissue donation and transplantation, critical care, trauma, emergency medicine, neurosurgery, medical education, information systems, senior hospital management and health service planning. See Appendix 1 for the list of Panel members and their affiliations.

The Panel was asked to advise the Ministry on a plan to provide Ontarians with equitable access to timely, appropriate and safe organ and tissue transplants. This includes identifying ways to increase donations and improve access to high quality, effective and efficient transplant care across Ontario. (See Appendix 2 for the Panel's terms of reference.) The development of a provincial transplant plan is part of Ontario's Wait

[7] *A Plan for Change and Action. Report of Premier Harris' Advisory Board on Organ and Tissue Donation* (Chair, Don Cherry), May 2000.
[8] Trillium Gift of Life Network: www.giftoflife.on.ca. Accessed June 18, 2009.

Time Strategy which is focused on improving access to and reducing wait times for a broad range of healthcare services. The Panel is advising the Minister of Health and Long-Term Care through Dr. Alan Hudson, Provincial Lead, Access to Services and Wait Times.

The Panel held four meetings in 2009 (January 12, February 23, April 6, June 8), along with 12 small working group meetings from March 12-30. The Panel was also invited to attend a symposium on reducing wait times and improving access to transplantation held in Toronto on May 4. Experts from Canada and the United States presented on donation and transplantation (see below).

3. METHODS USED TO INFORM THE PANEL'S WORK

A variety of methods was used to inform the Panel's deliberations and recommendations.

Literature and Data Review

Numerous published reports and documents on transplantation and related issues were reviewed. In addition, data on donation and transplantation were analysed from sources that included Trillium Gift of Life Network (Trillium), the Ministry of Health and Long-Term Care, and other sources. The literature and data are referenced in the footnotes.

Working Groups

Small working groups, made up of Panel members and Trillium resource staff, discussed and debated issues in detail. The groups and their tasks were as follows:

- Information Technology Working Group examined issues related to the use of information technology in transplant care.
- Organ Donation Issues Working Group identified ways in which donations could be increased.
- Pre- and Post-transplant Care Working Group examined the care provided to patients who are waiting for a transplant and those who have received a transplant.
- Public Awareness Working Group examined current and potential ways to increase donation awareness among the public.
- Tissue Working Group examined tissue donation issues and assessed Trillium's Tissue Strategic Plan completed in November 2006.[9]
- Transplant Issues Working Group examined the allocation of transplant organs and related transplant issues.

Each group met twice and presented its proposed directions to the Expert Panel for its consideration.

[9] Trillium Gift of Life Network. 2006 (November 6). *Strategic Plan to Improve Tissue Donation Activities in Ontario*.

Transplant Symposium, *Increasing Access and Reducing Wait Times for Transplantation in Ontario: The Path Forward* (May 4, 2009)

Panel members were invited to attend a Transplant Symposium held on May 4, 2009 in Toronto. Sponsored by the University of Toronto Transplantation Institute and the Ontario Ministry of Health and Long-Term Care, the symposium featured provincial, national and American experts speaking on donation in Ontario, barriers to donation and transplantation, lessons learned elsewhere and potential solutions. The Honourable Tommy Thompson, former Secretary for the United States Department of Health and Human Services, was the keynote speaker. A number of Panel members presented at the Symposium. In addition to bringing together the transplantation community, the event was meant to inform the work of the Panel.

4. OVERVIEW OF THE REPORT

The report begins by providing the context for the Panel's deliberations. This includes definitions of organ and tissue transplantation and an overview of the evolution of organised donation and transplantation efforts in Ontario (Section B: Chapters 5-6).

Section C presents a profile of transplantation in Ontario that includes organ donors and transplantation, tissue donors and transplantation, and funding to support transplantation (Chapters 7-9).

Section D presents the Panel's deliberations and recommendations on transplantation. Chapter 10 begins with an overview of a provincial integrated system to support the donor and transplant patients' journey. The major components of this system are outlined in subsequent chapters and include:

- More organ and tissue donors (Chapter 11) to be achieved with:
  - Public awareness and opportunities to donate (11.1)
  - Organisation and healthcare provider education and awareness (11.2)
  - Strong donation culture in hospitals supported with policies/processes, resources and information alerts (11.3)
  - Support and recognition for donors (11.4)
- Equitable access to organs and tissues based on clinical evidence (Chapter 12) that includes equitable access to organs based on clinical evidence; and an integrated approach to recover, process and access tissue (12.1-12.2).
- Organised transplant-related care (Chapter 13) that includes pre- and post-transplant care; resources for pre- and post-care; and reviews of transplant practices, appropriateness and outcomes (13.1-13.3).
- Accountability for performance (Chapter 14) which will be achieved with an information system (14.1); performance targets (14.2); and oversight for the system (14.3).

Section E presents an action plan and the consolidated list of recommendations (Chapters 15-16), followed by supporting appendices.

SECTION B: THE CONTEXT FOR THE EXPERT PANEL'S DELIBERATIONS

5. DEFINITIONS: UNDERSTANDING ORGAN AND TISSUE TRANSPLANTATION

5.1 ORGAN TRANSPLANTATION EXPLAINED

The first successful kidney transplant was preformed in Boston in 1954. This procedure was followed by the world's first successful lung transplant performed in Toronto in 1963, a liver transplant in Denver in 1967 and a heart transplant in the same year in Cape Town. Pancreatic and small intestine transplants soon followed. With time, the success of transplant procedures has increased and patient recovery rates have improved significantly.

Organ transplants are an option when an organ is failing. A transplant may be the best course of action for a person with kidney failure; a transplant is the only therapy for patients with end stage heart, lung or liver disease. Depending on the organ that is needed, a person may receive an organ from a deceased or living donor.

Deceased Organ Donation[10]

Historically, organs have been donated after brain death which is known as "*neurological determination of death*" (NDD).[11] Deceased organ donation can take place when someone has been declared NDD, a doctor has determined the organs can be used for transplant, and loved ones decide to artificially maintain vital organs by a ventilator to keep them suitable for transplant. An NDD donation can occur if someone suffers a severe aneurysm, stroke or head injury. The time from injury to diagnosis of neurological death varies from hours to many days, depending on the severity of the initial injury and the response to therapy.

"*Donation after cardiocirculatory death*" (DCD) can occur when the family/substitute decision maker and healthcare team decide to withdraw life-sustaining treatment because the patient has no hope of survival or meaningful functional status. In Europe and the United States, donation after cardiac death has been an option for families for over thirty years. In Ontario, DCD began in 2006.

[10] Trillium Gift of Life Network: www.giftoflife.on.ca. Accessed May 1, 2009.
[11] Canadian criteria for NDD have been established and are reported in Shemie, SD. 2006. "Severe brain injury to neurological determination of death: Canadian forum recommendations" *Canadian Medical Association Journal* 174(6 Supplement): S1-S30.

Living Organ Donation [12]

Living donation occurs when a living person donates an organ or part of an organ for transplant to another person. Living donors are most often family members or close friends of the recipient, however, other types of living donation are possible. These include anonymous donation, list exchange (a donor who is incompatible with his or her intended recipient offers to donate to a stranger), and paired exchange (two donors who are incompatible with their intended recipients, exchange recipients).

Living organ donation accounts for a significant proportion of the increase in organ donations in Ontario over the last ten years. The most common living donation is kidney which is the most successful of all transplant procedures. Advances in transplant medicine have made it possible to transplant a part of the liver (lobe), lung (lobe), small intestine and pancreas in a living donation. Other types of living donation are being investigated.

There are risks to being a living donor. A person who donates a kidney has a 0.03% chance of dying whereas a person who donates part of their liver has a 0.15% to 0.3% chance of dying.[13]

Outcomes of Organ Transplantation

A study of patients receiving long-term dialysis for end-stage renal disease found that transplant patients had a long-term mortality rate that was 48% to 82% lower than patients who were waiting for an organ.[14] The longer patients with end-stage renal disease who are on dialysis wait for a kidney, the worse their outcomes. One study found that the 10-year adjusted survival of kidney recipients (deceased donors) who had more than two years of dialysis was significantly worse than kidney recipients with less than six months of dialysis (39% and 69%, respectively).[15]

5.2 TISSUE TRANSPLANTATION EXPLAINED

Individuals who have certain illnesses or injuries may be helped with a tissue transplant. Transplanted human tissue can treat or cure a wide variety of health conditions. Cornea transplants can enable people to see again; cardiovascular tissue such as heart valves and veins can improve heart function; bone grafts and connective tissue such as tendons and

[12] Trillium Gift of Life Network: www.giftoflife.on.ca. Accessed May 1, 2009.
[13] David Grant. 2009 (May 4). "Living-Related Transplantation." Presentation at the Symposium: *Increasing Access and Reducing Wait Times for Transplantation in Ontario: The Path Forward*. Toronto, Ontario.
[14] Wolfe, RA et al. 1992 (December 2). "Comparison of Mortality in All Patients on Dialysis, Patients on Dialysis Awaiting Transplantation, and Recipients of a First Cadaveric Transplant" *New England Journal of Medicine* 341(23): 1725-1730.
[15] Meier-Kriesche et al. 2002 (November 27). "Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes: A Paired Donor Kidney Analysis" *Transplantation* 74(10): 1377-1381.

ligaments can be used to reconstruct bones and joints and help people become mobile again; and skin grafts can speed recovery from burns or accidents.

Corneas, skin, bone, cardiovascular tissue (heart valves and veins) and connective tissue (tendons, ligaments) are the most common types of tissue transplanted. One donor can provide tissue for as many as 75 recipients.

6. THE EVOLUTION OF ORGANISED DONATION AND TRANSPLANTATION EFFORTS IN ONTARIO

The evolution of organised donation and transplantation efforts in Ontario includes a number of organisations as well as reviews that focused on increasing the number of donations.

Metro Organ Retrieval and Exchange Program (1976)

Organised donation and transplantation efforts originally began in Ontario with the Metro Organ Retrieval and Exchange Program in 1976 (MORE). The Toronto General Hospital and the Kidney Foundation of Canada (Ontario Branch) supported four Toronto hospitals involved in kidney transplant in their efforts to: i) increase the number of kidneys for transplant and the number of organ donations by non-transplant centres; and ii) improve coordination and the use of harvested kidneys.

Multiple Organ Retrieval Exchange Program/Organ Donation Ontario (1984-1999)

The MORE program was expanded beyond the Toronto area. Hamilton and London became active members of the kidney procurement and distribution efforts, with Kingston and Ottawa joining soon afterwards. In 1984, the Metro Organ Retrieval and Exchange Program became known as the ***Multiple Organ Retrieval Exchange Program***. It was responsible for facilitating organ and tissue donation throughout Ontario. In 1999, MORE became known as ***Organ Donation Ontario*** (ODO). Responsible for promoting organ donation in the province, ODO's main duties were to operate computerized transplant waiting lists, promote organ and tissue donation, and oversee the implementation of standards and guidelines.

Advisory Board on Organ and Tissue Donation (2000)

In early 2000, Ontario's then Premier, Michael Harris, appointed Don Cherry to chair the Advisory Board on Organ and Tissue Donation.[16] The Board was charged with developing a comprehensive plan and strategy to double the organ donation rate by 2005. The Board made 16 recommendations that addressed: legislative and organisational requirements to increase donations; supports for living donors; tissue bank structures and funding; promotion and advertising; education and communications; and donor cards.

[16] *A Plan for Change and Action. Report of Premier Harris' Advisory Board on Organ and Tissue Donation* (Chair, Don Cherry), May 2000.

Trillium Gift of Life Network (2000)

The Advisory Board on Organ and Tissue Donation recommended that ***Trillium Gift of Life Network*** be created as a stand-alone entity with statutory authority, accountable to the Minister, led by a CEO and board of directors, and supported by a head office and regional offices (with in-hospital donation coordinators). The Board further recommended that Trillium become Ontario's "organ procurement organisation" to manage organ and tissue donation efforts in close co-operation with, but separately from, the transplant centres. In response to the Advisory Board report, the Ontario Government created the Trillium Gift of Life Network in December 2000, as Ontario's central organ and tissue donation agency.

Trillium is an operational service agency of the Ontario Government. Trillium is accountable to the Minister of Health and Long-Term Care in exercising its mandate but is not subject to the direct administrative control of Government or the Ministry. Trillium is a special Act corporation established under the *Trillium Gift of Life Network Act*. A *Memorandum of Understanding* (March 2002) between Trillium and the Minister clarifies operational, accountability, financial, administrative, auditing and reporting relationships. According to the *Trillium Act*, the *Corporations Act* does not apply to Trillium.

Trillium's vision is: To be a world-class organisation that enhances and saves lives through organ and tissue donation for transplantation.

Trillium's mission is: Saving and enhancing more lives through the gift of organ and tissue donation in Ontario.

According to the *Trillium Gift of Life Network Act*, the objects of the network are (8.8):

1. To plan, promote, co-ordinate and support activities relating to the donation of tissue for transplant and activities relating to education or research in connection with the donation of tissue.
2. To co-ordinate and support the work of designated facilities in connection with the donation and transplant of tissue.
3. To manage the procurement, distribution and delivery of tissue.
4. To establish and manage waiting lists for the transplant of tissue and to establish and manage a system to fairly allocate tissue that is available.
5. To make reasonable efforts to ensure that patients and their substitutes have appropriate information and opportunities to consider whether to consent to the donation of tissue and to facilitate the provision of that information.
6. To provide education to the public and to the health care community about matters relating to the donation and use of tissue and to facilitate the provision of such education by others.
7. To collect, analyse and publish information relating to the donation and use of tissue.
8. To advise the Minister on matters relating to the donation of tissue.

9. To do such other things as the Minister may direct. 2000, c. 39, s. 5.

Generally, Trillium tends to focus its efforts on promoting and managing donation, primarily deceased donations. Living donation is more the activity of the transplant centres.

Citizens Panel on Increasing Organ Donations (2007)[17]

In 2006, the Minister of Health and Long-Term Care, George Smitherman, established a Citizens Panel to hear the views and opinions of Ontarians on improving organ donation in Ontario. The Panel made 26 recommendations in the areas of law, education, the role of religion, donation after cardiac death, living donors, the living donor database, the hospital (the experience of donor families, hospital-specific issues, critical care, the intensivists' role), Local Health Integration Networks, the Trillium Gift of Life Network and National Issues.

[17] *The Citizens Panel on Increasing Organ Donations: Seeking views and opinions on increasing organ donations in Ontario* (Chair, Ted Boadway), March 2007.

SECTION C: THE PROFILE OF TRANSPLANTATION IN ONTARIO

7. ORGAN DONORS AND TRANSPLANTATION

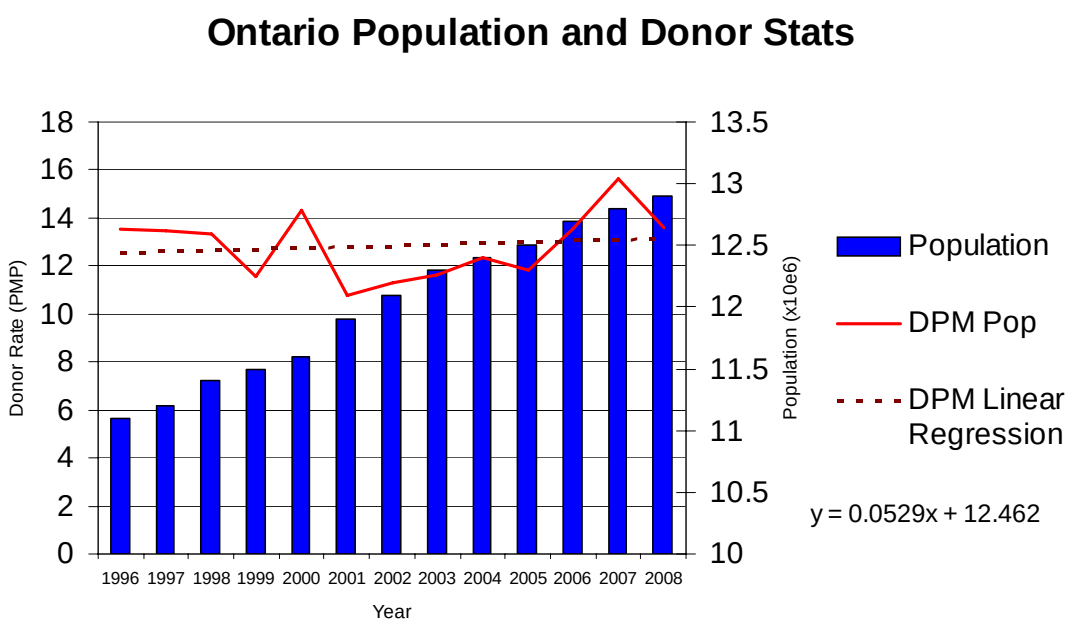
This chapter presents information on:
- Organ Donors (7.1)
- Organ Transplant Services and Organ Transplants (7.2)
- Waiting Times for Organs (7.3)

7.1 ORGAN DONORS

Rates of Donation

In 1996, Ontario's organ donation rate was 13.8 donations per million population (Figure 1). Over 12 years, the donation rate varied from a low of 10.8 per million in 2001 to a high of 15.8 per million in 2007. By 2008, the rate was similar to that in 1996: 13.8 per million population.

Figure 1: Ontario Organ Donations Per Million (DPM) Population, 1996-2008



DPM Pop: Donations per Million Population Source: Dr. Gary Levy, Trillium Gift of Life Network Data

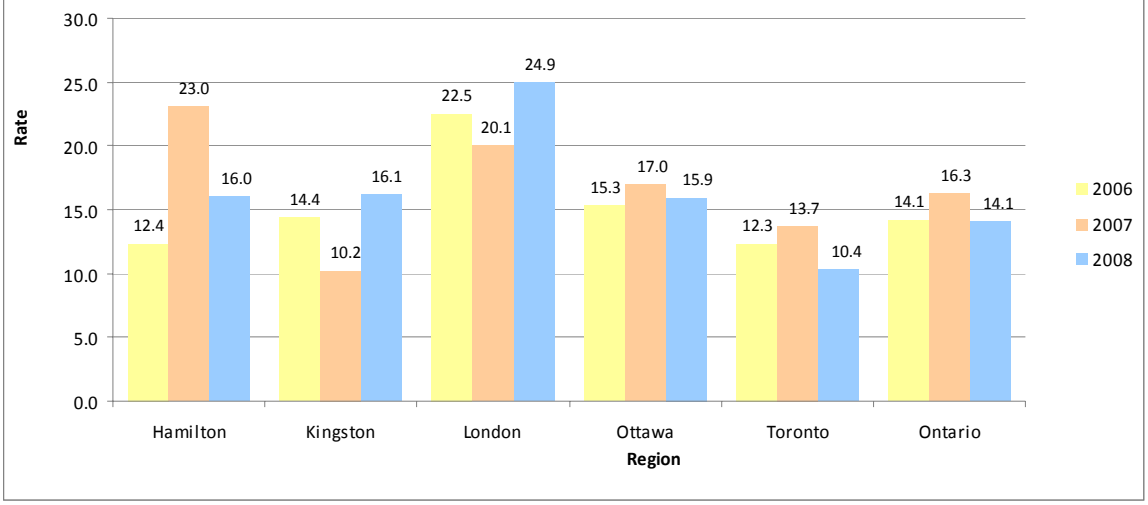
The rate of donations is not keeping up with the growth of the population. A linear regression analysis – used to assess donation rates taking into account the growth of the

population – found that ***Ontario's organ donation rate has remained fairly steady from 1996 to 2008*** (Figure 1).

In 2005, ***Ontario's donation rate per million population was below the Canadian average*** (11.75 per million compared to 13 per million). In 2006 and 2008, Ontario's donation rate was 14.1 per million with a higher rate of 16.3 in 2007 (Figure 2).

Within Ontario, donation rates vary dramatically by region (Figure 2). In 2008, Toronto had the lowest organ donation rate of 10.4 per million population compared to higher rates of about 16 in Hamilton, Kingston and Ottawa, and 24.9 in London. From 2006 to 2008, no Ontario region showed a consistent increase in donation rates per million population; rather rates increased or decreased over the three years depending on the region.

Figure 2: Organ Donations Per Million Population, Ontario Regions, 2006-2008



Source: Trillium Gift of Life Network. Donor counts extracted from TOTAL by Michael Dutta, June 17-18, 2009. Population from Statistics Canada 2006 Census and Ontario Ministry of Finance projections.

Although the focus of the Expert Panel's work is Ontario, it is noted that Canada's deceased donation rate per million population is lower compared to most other western countries.[18] In *2005*, Canada's deceased donations per million population (PMP) was 13, compared to 35 in Spain, 25 in Austria, 24 in Belgium, 22 in France, 21 in Italy and 25.5 in the United States. In 2008, the US rate was 27.8 PMP compared to 14.1 PMP in Ontario. International comparisons must be used with caution since a common definition of "number of donors per million population" does not exist.[19] For example, Canada

[18] Trillium Gift of Life Network: Data From the Council of Europe, 2006.
[19] Barnieh, L. et al., 2006. "Benchmarking performance in organ donation programs: dependence on demographics and mortality rates" *Canadian Journal of Anesth* 53(7): 727-731.

defines a deceased donor as someone where "at least one solid organ has been used for transplant."[20] Most European countries and the United States define a deceased donor as someone where "at least one vascularized solid organ was recovered for the purposes of organ transplantation."[21] This means that a donor is counted even if the organs are not used. Although different methods are used to calculate donation rates, it has been concluded that several countries consistently have high rates of donation: Spain, Austria, Belgium, Norway, France, Switzerland, Portugal, Italy and the United States.[22]

Number and Type of Organ Donors

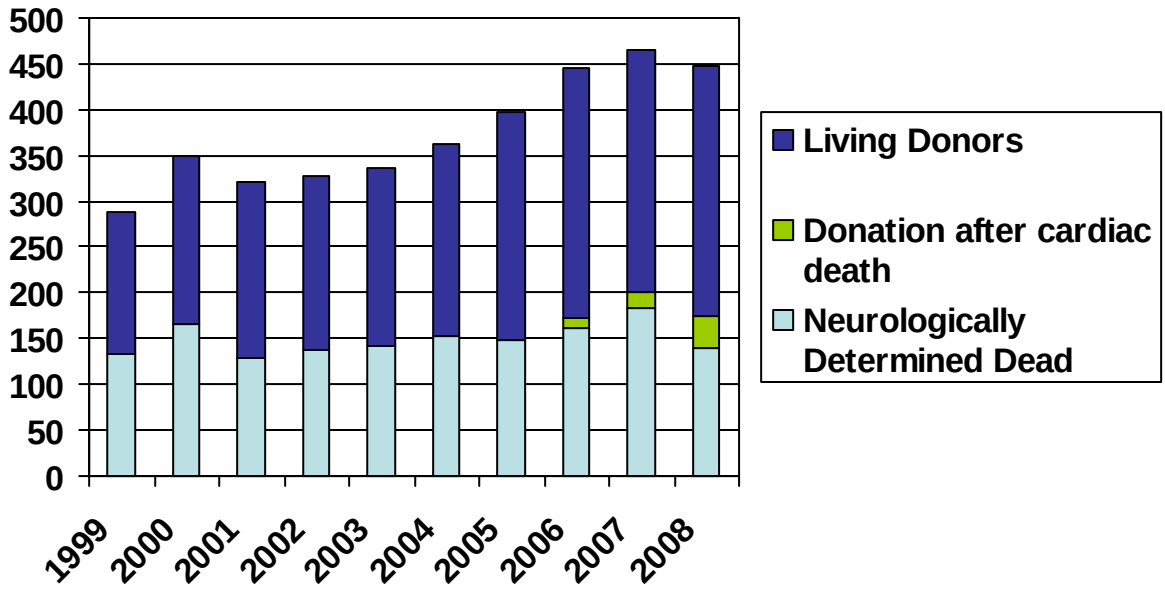
The number of organ donors has increased in Ontario with the majority of this increase due to more living donors. Between 1999 and 2008, the number of deceased and living organ donors in Ontario increased 55% from 289 donors to 447 donors (Figure 3). In this time period, the number of deceased organ donors increased 32% compared to a 74% increase in the number of living donors.

Although the number of living donors appears to be steadily increasing since 1999, there have been larger increases in deceased donors over the past three years. From 2006 to 2008, Ontario has averaged 182 deceased donors each year (172, 200, 175 donors, respectively), compared to an average of 144 donors each year between 1999 and 2005.

The proportion of living donors is now larger than the proportion of deceased donors. Organ donors after cardiac death began in Ontario in 2006. Over three years, the proportion of donors after cardiac death has been gradually increasing.

[20] Canadian Organ Replacement Registry. 2002. *CORR Annual Reports*. Ottawa: Canadian Institute for Health Information.
[21] Committee on Increasing Rates of Organ Donation, Board on Health Sciences Policy, United States Institute of Medicine. 2006 (May 2). *Organ Donation: Opportunities for Action*. Washington: The National Academies Press.
[22] Committee on Increasing Rates of Organ Donation, Board on Health Sciences Policy, United States Institute of Medicine. 2006 (May 2). *Organ Donation: Opportunities for Action*. Washington: The National Academies Press.

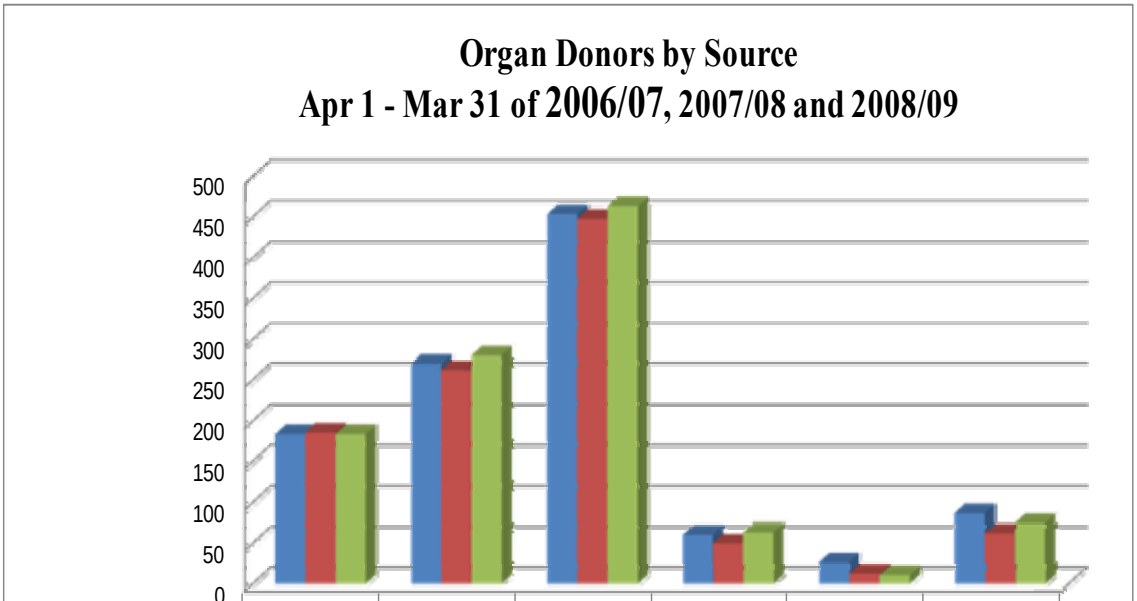
Figure 3: Type of Organ Donors in Ontario, 1999-2008



Source: Dr. Gary Levy. Trillium Gift of Life Network Data

Although Ontario benefits from organ donors from other provinces and the United States, these donors make up a very small proportion of all organ donors in the province (Figure 4)

Figure 4: Organ Donors by Source of Organ, April 1-March 31, 2006/07-2008/09



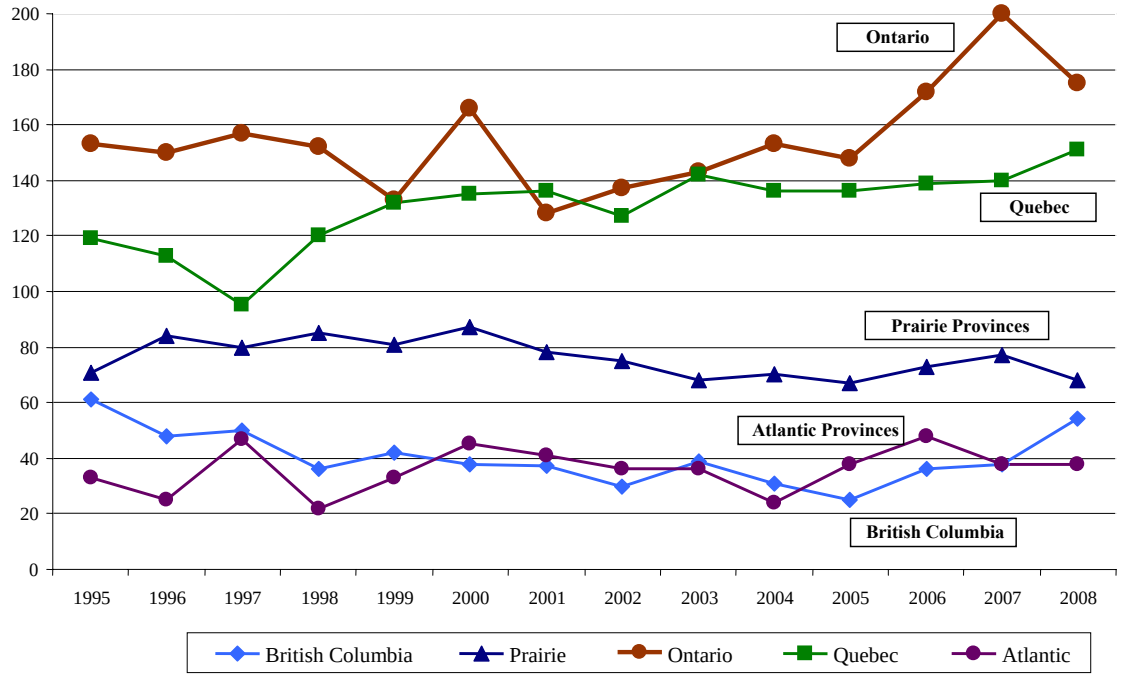
	Deceased Donors from Ontario	Living Donors from Ontario	All Ontario Donors	Deceased Donors from Other Canadian Provinces	Deceased Donors from the US	All Out-of-Province Donors
Apr 1 - Mar 31, 2006/07	184	270	454	61	26	87
Apr 1 - Mar 31, 2007/08	186	262	448	50	13	63
Apr 1 - Mar 31, 2008/09	184	280	464	64	11	75

Source: Trillium Gift of Life Network. Note: The table presents absolute number of donors rather than rates and, therefore, is not adjusted for population.

Compared to other provinces, Ontario has the largest number of deceased organ donors which is not surprising given that Ontario has the largest population (Figure 5).

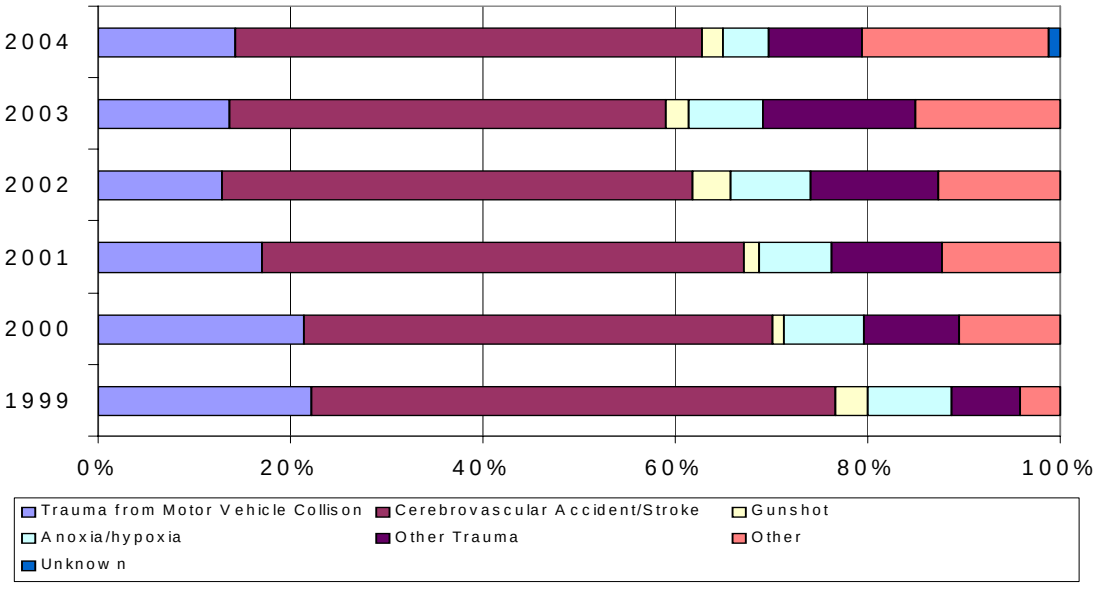
The cause of death for deceased donors has been gradually shifting in Canada (Figure 6). From 1999 to 2004, the proportion of donors who died due to trauma from motor vehicle collisions has decreased. This is due to stricter laws on impaired driving, speeding and use of seat belts and vehicle air bags.

Figure 5: Number of Deceased Organ Donors by Province/Region, 1995-2008



Source: Trillium Gift of Life Network. Note: These figures do not reflect rates adjusted for population.

Figure 6: Deceased Donors in Canada by Cause of Death, 1999-2004



Source: Trillium Gift of Life Network

It has been suggested that ethno-racial factors may impact on organ donation rates. Trillium Gift of Life Network conducted an informal study where coordinators surmised the ethno-racial background of individuals consenting to deceased organ donation between January 2005 to December 2007.[23] Coordinators assessed individuals as being either Caucasian or Other. The unpublished study concluded that 86% of individuals who were identified as "Caucasian" consented to deceased organ donation compared to 48% of individuals identified as "Other". Although these findings are not based on a rigorous methodology, they do suggest that ethno-racial factors may impact on deceased donations. The impact may be different for living donation.

Referral of Deceased Organ Donors and Actual Number of Donors

The number of deceased organ donors that are referred to Trillium Gift of Life Network is higher than the number of actual donors. Trillium uses a number of measures to track donors beginning with probable donation cases (referral rate) to actual donated organs (conversion rate). The measures are:

- Referral Rate: Probable cases referred to Trillium
- Declaration Rate: Probable cases declared neurologically dead
- Approach Rate: Probable cases where families are approached
- Consent Rate: Cases where consent was obtained from probable cases
- Recovery Rate: Actual donors from those declared and consented
- Conversion Rate: Actual donors from potential eligible cases

Table 1 presents the deceased donors in Ontario from probable cases that were referred to Trillium by ***Tier 1*** hospitals to the final number of actual donors. (There are 21 Tier 1 hospitals as presented in Appendix 4.) Table 1 also includes the measures noted above. Out of 380 probable deceased donors referred to Trillium in 2008/09, there were 161 actual donors. This reflects a 50% conversion rate (proportion of actual donors from potential eligible cases).

When probable cases referred to Trillium from ***all hospitals*** in Ontario are examined, the conversion rate is higher. From February 2008 to January 2009, there were 181 eligible deaths where donation was possible in Ontario. Of these, 75.6% became actual donors. Ontario's conversion rate is higher than a United States average conversion rate of 71.1% of 9,783 eligible deaths in nine organ procurement agencies. Of these agencies, conversion rates ranged from a low of 52.9% in the New York Organ Donor Network (434 eligible deaths) to a high of 77.7% in Gift of Life Philadelphia (442 eligible deaths).[24]

[23] Frank Markel, 2009 (May 4). "Performance Measures in Organ Donation in Ontario." Presentation at the Symposium: *Increasing Access and Reducing Wait Times for Transplantation in Ontario: The Path Forward*. Toronto, Ontario.

[24] Frank Markel, 2009 (May 4). "Performance Measures in Organ Donation in Ontario." Presentation at the Symposium: *Increasing Access and Reducing Wait Times for Transplantation in Ontario: The Path Forward*. Toronto, Ontario.

Table 1: Deceased Donors From Probable Cases Referred to Trillium Gift of Life Network by Tier 1 Hospitals to Actual Donors, 2008-2009 *	
Probable Cases	380
Exclusions From Probable Cases**	55
Potential Eligible Cases	325
Donors	161
Referral Rate	96%
Declaration Rate	72%
Approach Rate	83%
Consent Rate	66%
Recovery Rate	85%
Conversion Rate	50%

Source: Trillium Gift of Life Network.
*Tier 1 hospitals include Children's Hospital of Eastern Ontario, Grand River Hospital, Hamilton Health Sciences Centre (3 sites), Hopital Regional de Sudbury Regional Hospital, Hospital for Sick Children, Hotel Dieu Grace Hospital, Kingston General Hospital, Lakeridge Health Sciences (Oshawa site), London Health Sciences Centre (3 sites), Niagara Health System, Ottawa Hospital (2 sites), Royal Victoria Hospital, St. Mary's General Hospital, St. Michael's Hospital, Sunnybrook Health Sciences, The Scarborough Hospital, Thunder Bay Regional Health Sciences Centre, Trillium Health Centre, University Health Network (Western and General), William Osler Health Centre, York Central Hospital.
**Includes cases not approached because of medical unsuitability or no next of kin, cases found medically unsuitable post-consent, and cases declined by the Coroner.

7.2 ORGAN TRANSPLANT SERVICES AND ORGAN TRANSPLANTS

Organ Transplant Services

Seven hospitals in Ontario perform organ transplants on eight hospital sites.[25] All hospitals are university-affiliated academic health science centres (Table 2). The Hospital for Sick Children performs paediatric transplants whereas all other hospital sites perform adult transplants. Five adult hospital sites performed only one type of transplant between 2006-2008:

- Kingston General, St. Joseph's Healthcare Hamilton, St. Michael's and The Ottawa General transplanted kidneys; and
- The University of Ottawa Heart Institute transplanted hearts.

There are no transplant centres in Northern Ontario.

Three hospitals in Ontario developed multi-organ transplant programs. Between 2006-2008:

- University Health Network performed 10 types of adult transplants;
- The Hospital for Sick Children performed seven types of paediatric transplants; and
- London Health Sciences Centre performed four types of adult organ transplants.

[25] Ontario has 155 public hospital corporations operating on 211 sites.

Table 2: Hospitals in Ontario That Performed Organ Transplants by Type of Organ Transplanted, 2006-2008

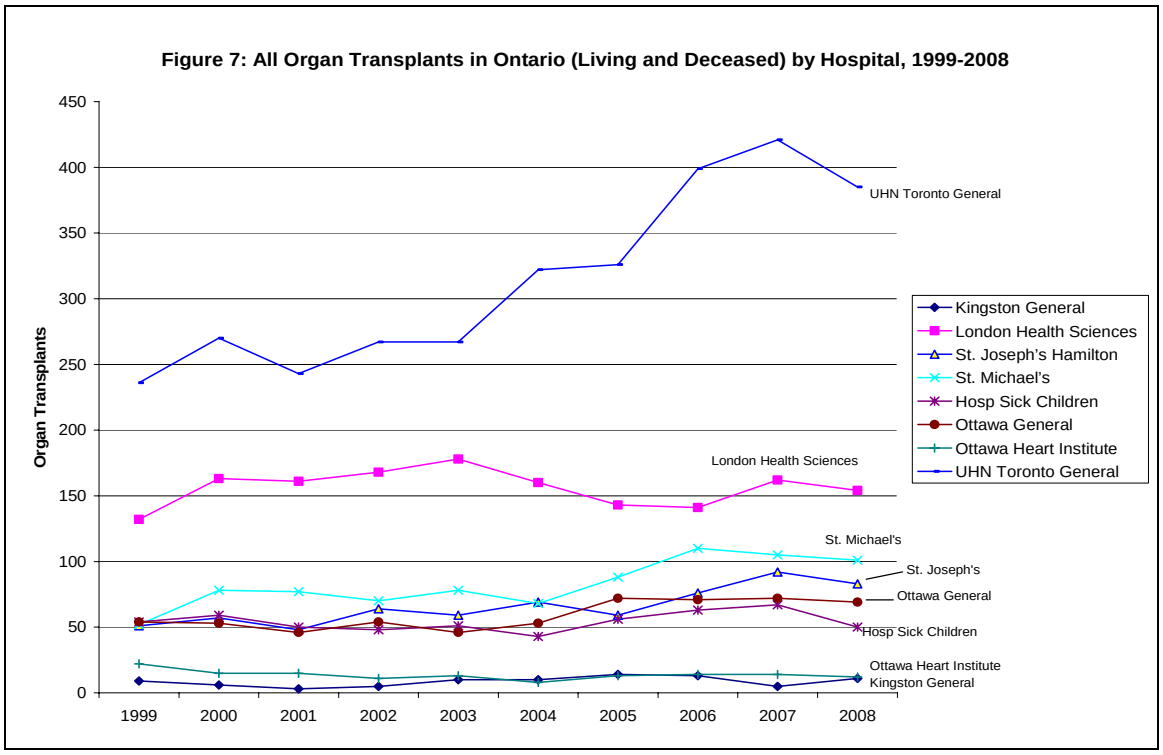
Organ	Hospital							
	Kingston General Hospital	London Health Sciences Centre (University Hospital)	St. Joseph's Healthcare, Hamilton	St. Michael's Hospital	The Hospital for Sick Children	The Ottawa Hospital (Ottawa General Hospital)	The Ottawa Hospital (University of Ottawa Heart Institute)	University Health Network (Toronto General Hospital)
Kidney	√	√	√	√	√	√		√
Liver		√			√			√
Lung					√			√
Heart		√			√		√	√
Pancreas								√
Small Bowel					√			√
Kidney-Pancreas		√						√
Heart-Lung								√
Liver-Kidney					√			√
Liver-Bowel					√			
Liver-Heart								√

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

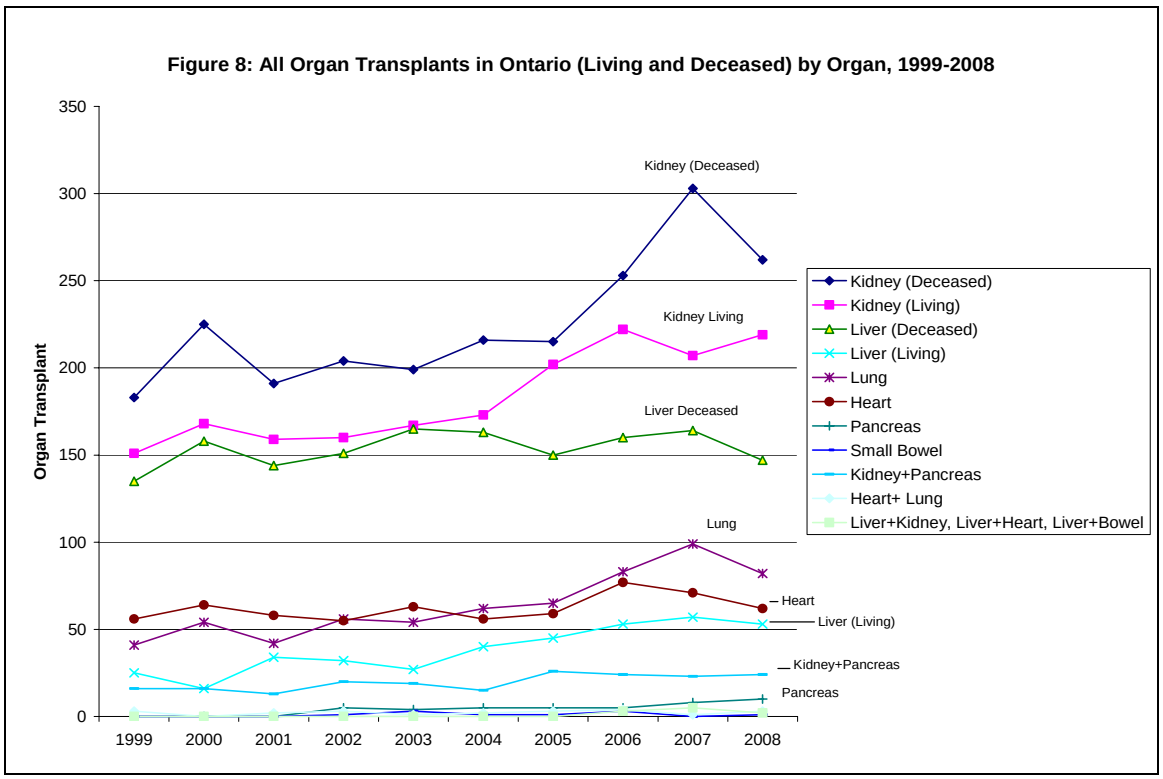
Organ Transplants

Figure 7 presents all the organ transplants performed from 1999 to 2008 by each Ontario hospital (see Appendix 3, Table 21). The total number of living and deceased organ transplants increased 42% from 1999 to 2008 (610 to 865 transplants). UHN Toronto is the largest transplant site followed by London Health Sciences. The smallest transplant centre is Kingston General Hospital and the Ottawa Heart Institute. All the transplant centres except for Kingston performed fewer transplants in 2008 compared to 2007. Generally, Kingston performs the smallest number of transplants of all the centres (e.g., five in 2007; 11 in 2008).

Figure 8 presents all the organ transplants performed from 1999 to 2008 by organ (see Appendix 3, Table 22). Kidney (deceased and living) account for the largest number of transplants followed by deceased donor liver.



Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

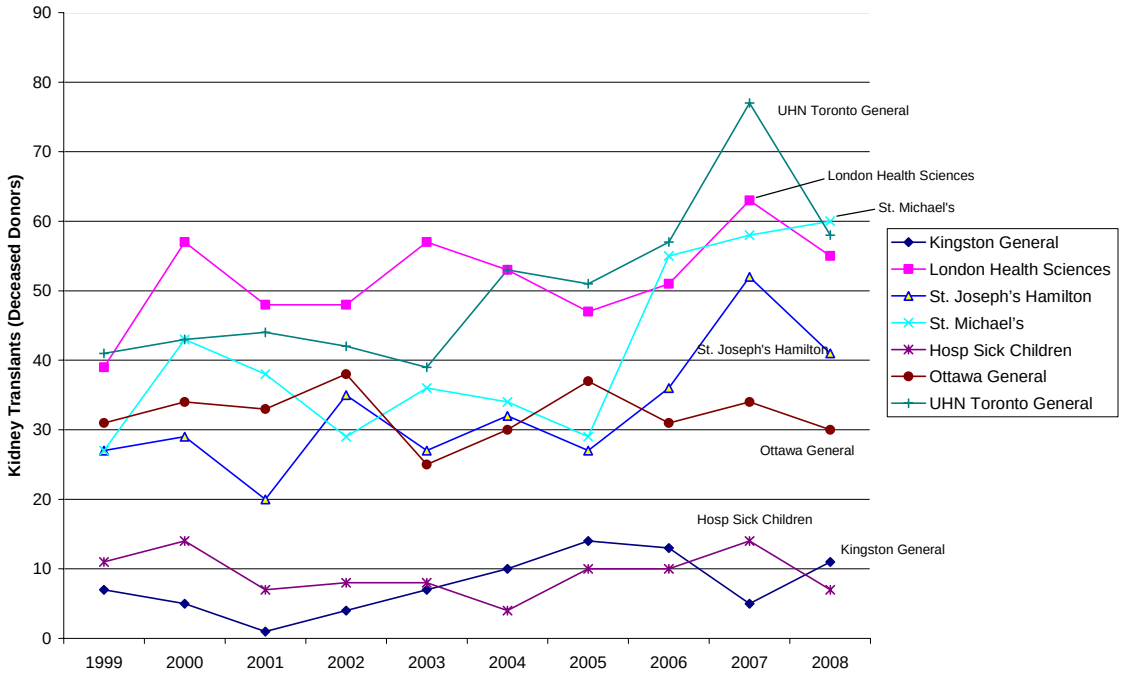


Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Figure 9 presents the number of kidney transplants from ***deceased*** donors from 1999 to 2008 by each Ontario hospital (see Appendix 3, Table 23).

The trends are quite erratic with increases over time evident at sites such as St. Michael's, UHN Toronto, London Health Sciences and St. Joseph's Hamilton. Ottawa General, Sick Children and Kingston General appear to be relatively stable.

Figure 9: Kidney Transplants in Ontario (Deceased) by Hospital, 1999-2008

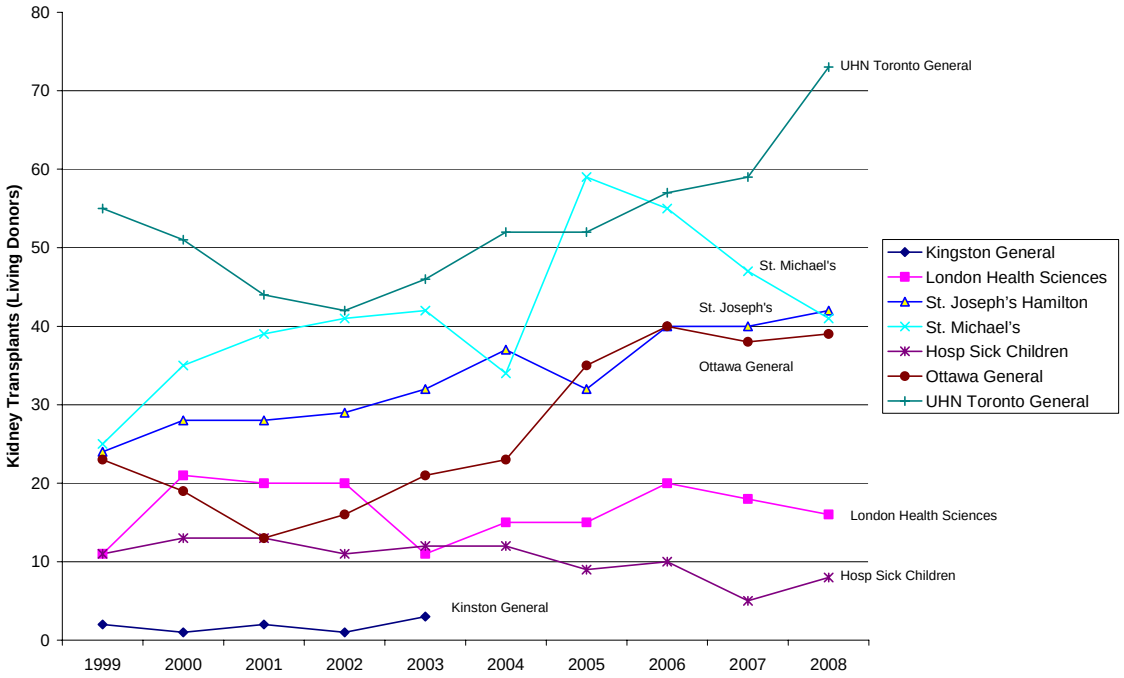


Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Figure 10 presents the number of kidney transplants from ***living*** donors from 1999 to 2008 by each Ontario hospital (see Appendix 3, Table 24).

The largest and steadiest increases in living kidney transplants from 1999 to 2008 appear to be at St. Joseph's Hamilton and Ottawa General (70%). UHN Toronto has a steady increase from 2002 onward. All other facilities appear to have held steady or decreased living kidney transplants from 1999 to 2008.

Figure 10: Kidney Transplants in Ontario (Living) by Hospital, 1999-2008



Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Figure 11 presents the number of liver transplants from ***deceased*** donors from 1999 to 2008 by each Ontario hospital (see Appendix 3, Table 25).

The number of deceased liver transplants at the three liver transplant sites – UHN Toronto, London Health Sciences and the Hospital for Sick Children – were fairly similar in 1999 and 2008 despite an increase in Ontario's population.

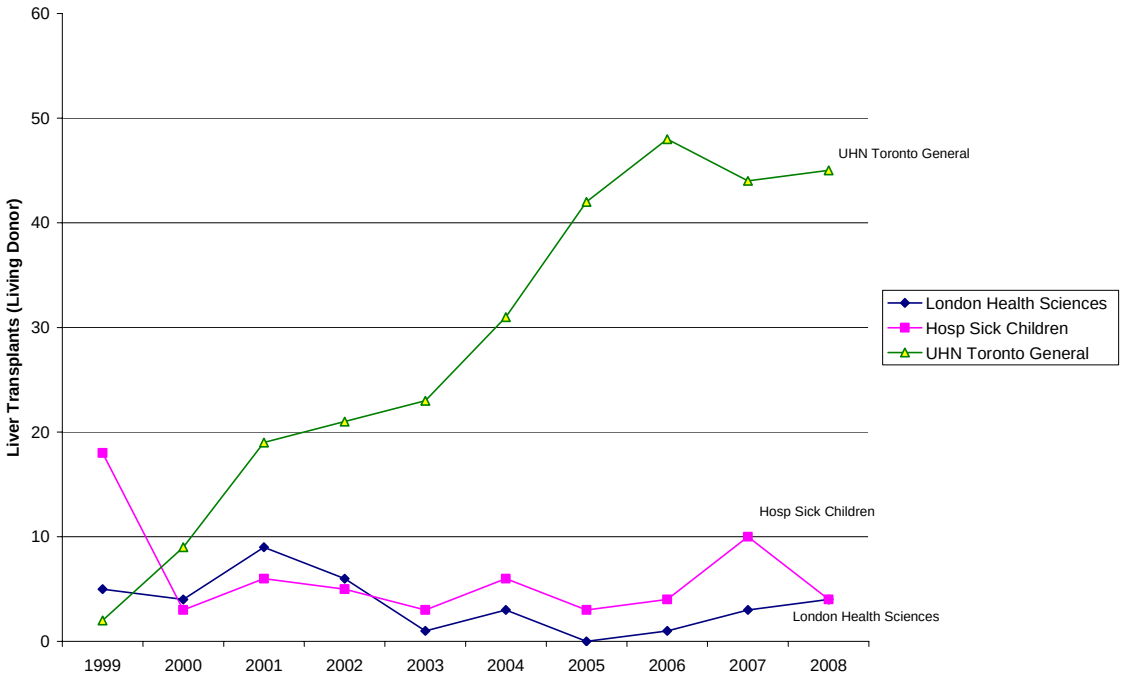
Figure 11: Liver Transplants in Ontario (Deceased) by Hospital, 1999-2008

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Figure 12 presents the number of liver transplants from ***living*** donors from 1999 to 2008 by each Ontario hospital that performs this procedure (see Appendix 3, Table 26).

UHN Toronto General has had a dramatic increase in living donor liver transplants over 10 years. In contrast, the number of living donor transplants has decreased at the Hospital for Sick Children and remained steady at London Health Sciences.

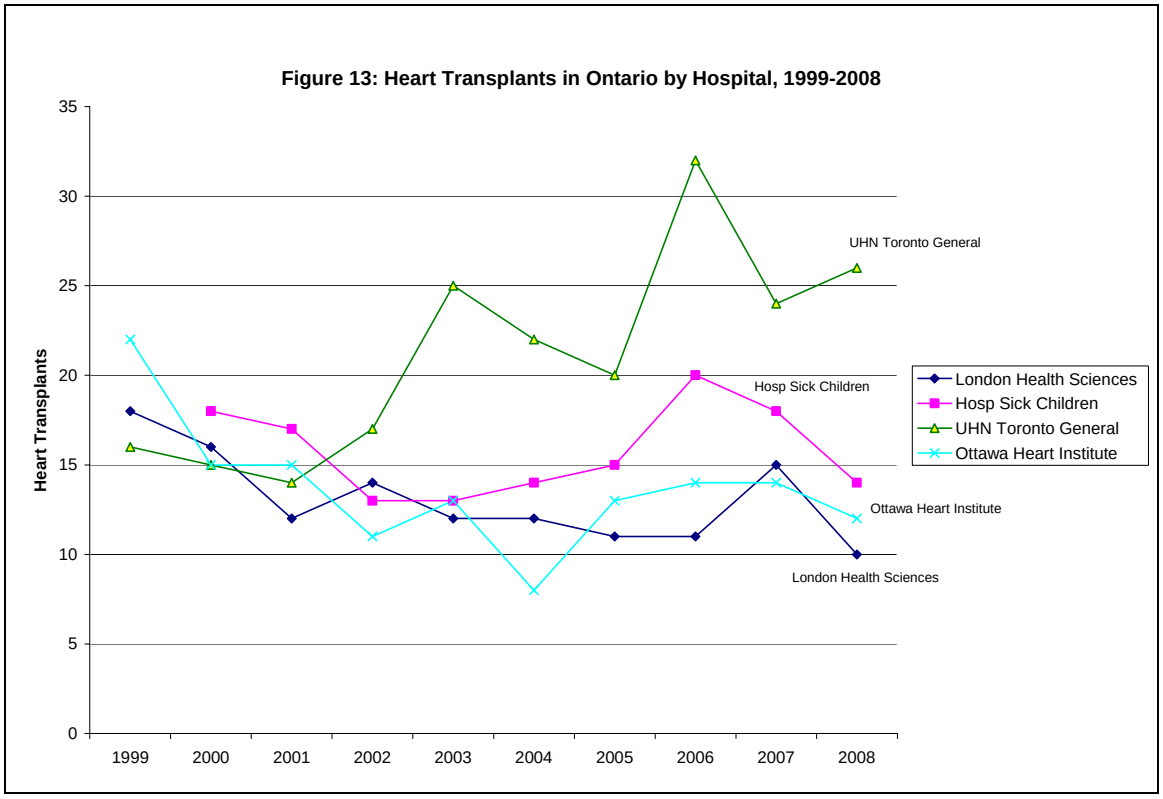
Figure 12: Liver Transplants in Ontario (Living) by Hospital, 1999-2008



Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Figure 13 presents the heart transplants performed from 1999 to 2008 by each Ontario hospital that performs this procedure (see Appendix 3, Table 27).

Although UHN Toronto General's trend has been erratic, the overall trend is one of increasing growth. In contrast, the other three centres – Ottawa Heart, London Health Sciences and the Hospital for Sick Children – have experienced decreases in the number of heart transplants performed over 10 years.



Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Tables 3 and 4 present other transplants that were performed in Ontario from 1999-2008.

Table 3: Selected Organ Transplants in Ontario by Organ and Hospital, 1999-2008

	Lung			Pancreas	Small Bowel			Liver+ Bowel
	London Health Sciences	Hosp Sick Children	UHN Toronto General	UHN Toronto General	London Health Sciences	Hosp Sick Children	UHN Toronto General	Hosp Sick Children
1999	5	3	33					
2000	4	1	49					
2001	2	2	38					
2002		3	53	5	1			
2003		1	53	4	1	2		
2004		2	60	5			1	
2005		3	62	5			1	
2006		3	80	5		1	2	3
2007		4	95	8				2
2008		4	78	10		1		1
Total	**11**	**26**	**601**	**42**	**2**	**4**	**4**	**6**

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 4: Selected Organ Transplants in Ontario by Organ and Hospital, 1999-2008

	Kidney+Pancreas			Heart+Lung			Liver+Kidney, Liver+Heart	
	London Health Sciences	Hosp Sick Children	UHN Toronto General	London Health Sciences	Hosp Sick Children	UHN Toronto General	Hosp Sick Children	UHN Toronto General
1999			16	1		2		
2000			16					
2001			13			2		
2002			20			3		
2003			19	1				
2004	4		11			2		
2005	3		23			3		
2006	7		17			4		
2007	4		19			1	1	2
2008	10		14			3		1
Total	**28**		**168**	**2**		**20**	**1**	**3**

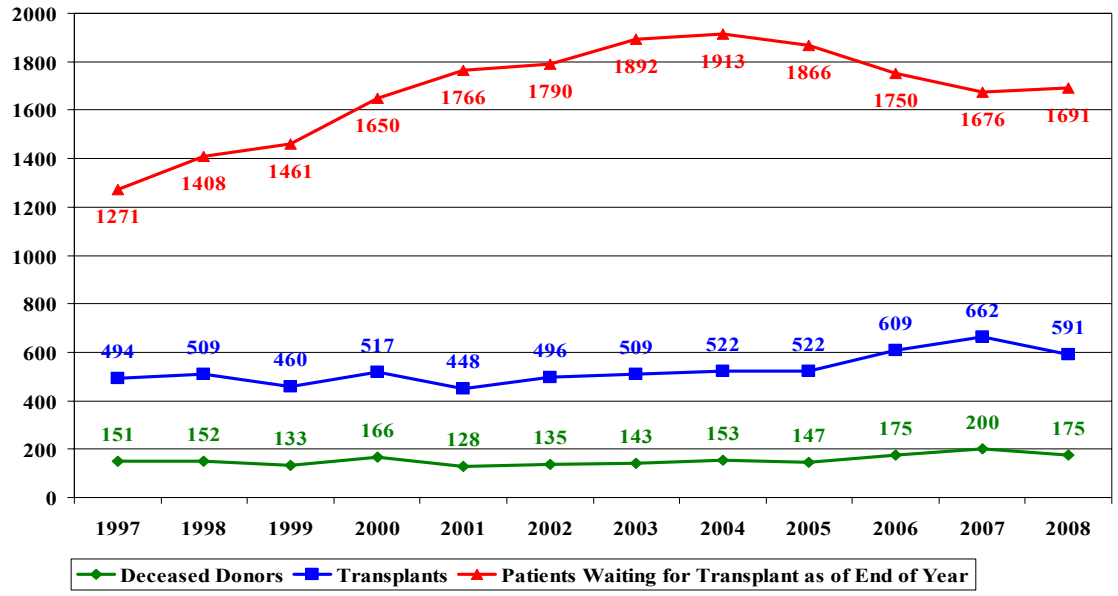
Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

7.3 WAITING TIMES FOR ORGANS

Patients Waiting For an Organ

Many people are on organ transplant waiting lists in Ontario. Figure 14 indicates that at the end of 2008, 1,691 patients were on an organ transplant waiting list. Generally, the number of people on an organ transplant waiting list increased from 1997 to 2004 but appears to have steadily decreased from 2004 to 2007. The number of people waiting increased in 2008.

Figure 14: Deceased Organ Donation, Deceased Transplantation and Patients Waiting for an Organ in Ontario, 1997-2008



Source: Trillium Gift of Life Network

The organ waiting list with the most number of people is kidneys (Table 5). Of 1,680 people in Ontario on organ waiting lists on May 27, 2009, 71% were waiting for a kidney. The next largest group was individuals waiting for a liver (18%).

Table 5: Number of Ontarians on Organ Wait Lists by Organ, May 27, 2009

Organ(s)	Individuals on Waiting List	
	Number	Percentage
Heart	51	3.0%
Kidney	1,200	71.4%
Liver	304	18.1%
Lung	58	3.5%
Pancreas	23	1.4%
Small Bowel	4	.2%
Heart Lung	1	.06%
Kidney Pancreas	39	2.3%
Total	**1,680**	**100%**

Source: Trillium Gift of Life Network: www.giftoflife.on.ca. Accessed May 27, 2009.

Many factors impact on the length of time a patient waits for a transplant. When an organ becomes available factors that are considered when picking the best matched potential recipient may include blood type, size of the organ, medical urgency of the patient, the degree of immune-system match between donor and recipient, and other factors. All of these can impact on how long a person waits for an organ.

Patients Waiting for a Kidney

Wait time for a kidney begins from the date a person starts dialysis (list date) and ends when the transplant is received. The time spent waiting for a kidney transplant is impacted by the hospital where the transplant will take place and whether the donor is living or deceased.

Individuals who received a deceased donor kidney transplant in Ontario in 2008 waited an average of about five years for an organ 1,806 days (Table 6). The median wait time was 4.7 years or 1,730 days.

Table 6: Wait Time of Patients Who Received Deceased Donor Kidney Transplants in Ontario (Days), 2006, 2007 and 2008*

	2006	2007	2008
Number of Patients	249	289	242
Average Wait in Days	1,865	1,777	1,806
Median Wait in Days	1,835	1,829	1,730
Minimum-Maximum Wait in Days	0-8,324	2-4,723	6-6,959

Source: Trillium Gift of Life Network. Raw data extracted from TOTAL on Feb 5, 2009 by Michael Dutta. Summarized on March 13, 2009 by Jason Lian.

*Wait time is measured as the number of days waited from List Date (date on which dialysis started) to the Transplant Date.

The wait time varied significantly depending on the hospital where the deceased donor kidney was obtained (Table 7). Adult patients at London Health Sciences waited significantly less time for a deceased donor kidney (median wait of 2.5 years or 905 days)

compared to the median wait time of patients in the major transplant centres in Ottawa (4.1 years), UHN Toronto General (4.4 years), Hamilton (5.1 years) and Toronto St. Michael's (6.9 years). Between 2006 and 2008, Toronto University Health Network and Hamilton significantly reduced their wait times for deceased donor kidneys by 1.4 years and 1 year, respectively. Paediatric patients also waited significantly less time for a deceased donor kidney in 2008 compared to 2006 (median wait of 74 days compared to 388 days).

Table 7 indicates that some patients who received a deceased donor kidney waited significantly long periods of time. For example, the maximum time a person waited before receiving a kidney in 2008 was 6,959 days or 19 years.

Table 7: Wait Time of Patients Who Received Deceased Donor Kidney Transplants in Ontario (Days) by Hospital, 2006, 2007 and 2008*

Hospital	Number of Patients		
	2006	2007	2008
Kingston General	12	5	11
London Health Sciences	48	61	51
Ottawa Hospital	31	34	30
St. Joseph's Hamilton	36	47	36
St. Michael's	55	57	56
The Hospital for Sick Children	10	9	6
UHN Toronto General	57	76	52
Total Number of Patients	**249**	**289**	**242**
	Average and (Median) Wait in Days		
	2006	**2007**	**2008**
Kingston General	1,254 (924)	530 (180)	679 (502)
London Health Sciences	1,017 (761)	1,113 (814)	1,171 (905)
Ottawa Hospital	1,544 (1,280)	1,423 (1,440)	1,772 (1,500)
St. Joseph's Hamilton	2,189 (2,220)	1,998 (1,974)	1,855 (1,852)
St. Michael's	2,700 (2,679)	2,459 (2,600)	2,562 (2,504)
The Hospital for Sick Children	410 (388)	163 (11)	130 (74)
UHN Toronto General	2,129 (2,124)	2,092 (2,126)	2,030 (1,614)
Average and (Median) Wait in Days Ontario	**1,865 (1,835)**	**1,777 (1,829)**	**1,806 (1,730)**
	Minimum-Maximum Wait in Days		
	2006	**2007**	**2008**
Kingston General	659-2,738	129-1472	47-1,559
London Health Sciences	0-7,160	58-3774	20-3,984
Ottawa Hospital	810-4,394	530-2787	261-6,687
St. Joseph's Hamilton	450-8,324	603-3414	144-3,234
St. Michael's	904-3,851	905-3690	1479-5,509
The Hospital for Sick Children	195-792	2-704	6-406
UHN Toronto General	0-4,261	61-4723	149-6,959
Minimum-Maximum Wait in Days	**0-8,324**	**2-4723**	**6-6,959**

Source: Trillium Gift of Life Network. Raw data extracted from TOTAL on Feb 5, 2009 by Michael Dutta. Summarized on March 13, 2009 by Jason Lian.

*Wait time is measured as the number of days waited from List Date (date on which dialysis started) to the Transplant Date.

The difference in wait times for deceased donor kidney transplants across Ontario appears to depend mainly on the deceased donor rate in each region.[26] As Figure 2 showed, London had the highest organ donations per million population in Ontario in 2008 (24.9). This major transplant centre has the shortest wait time for deceased donor kidney transplants (Table 7). Other factors such as referral rates of patients on dialysis to transplant centres and listing practices (patients who are put on a transplant list) do not appear to be significantly different between centres to have an impact on waiting times (Table 8).

Table 8: Average Annual Referrals of Dialysis Patients to Ontario Transplant Centres and Kidney Transplants by Centre of the Dialysis Population, 2006-2008 (Average Annual)

Hospital	Patients on Dialysis	Patients on Dialysis Referred to Transplant Centre for Evaluation		All Kidney Transplants (Average Annual)		Deceased Kidney Transplants (Average Annual)		Living Kidney Transplants (Average Annual)	
		#	% *	#	Transplants / Dialysis Patients %	#	Deceased Transplants /Dialysis Patients %	#	Living Transplants /Dialysis Patients %
Kingston General	374	34 +	9.1	6	1.7*	6	1.7*	0	0*
London Health Sciences	1,147	120	10.5	74	6.4	56	4.9	18	1.6
Ottawa Hospital	930	82	8.9	71	7.6	32	3.4	39	4.2
St. Joseph's Hamilton	1,407	177	12.6	84	6.0	43	3.1	41	2.9
Toronto Centre ~	5,328	405	7.6	232	4.3	121	2.2	111	2.1
Ontario	**9,186**	**818**	**8.9%**	**467**	**5.1%**	**258**	**2.8%**	**209**	**2.3%**

Source: Dr. Jeffrey Zaltzman.

* Based on the prevalence of dialysis. The referral rate is much lower than the List Rate since these patients wait years for a transplant.

+ A number of Kingston's patients are referred to and transplanted in Toronto and Ottawa.

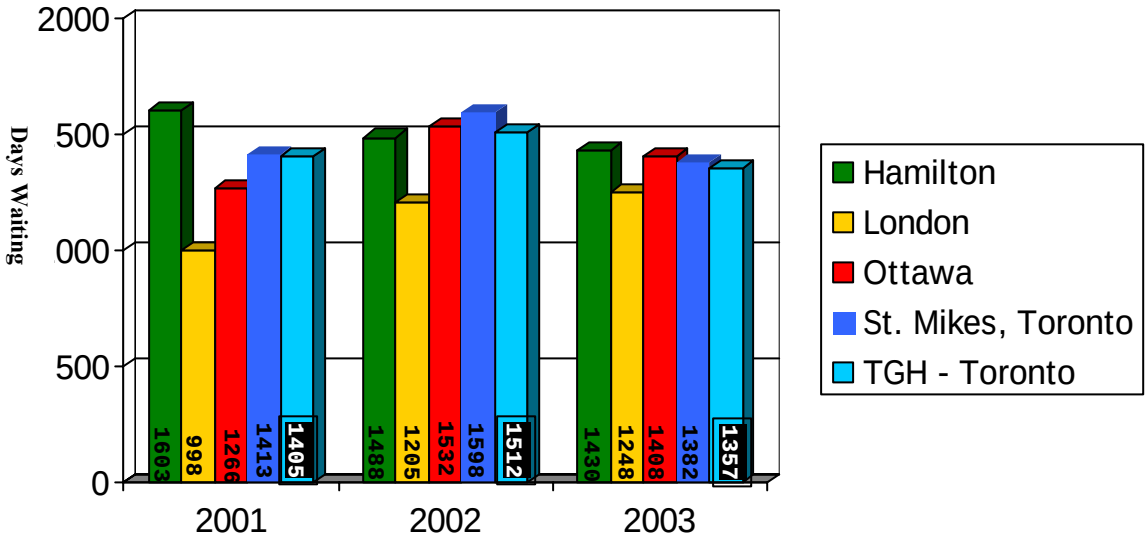
~ St. Michael's Hospital and University Health Network (Toronto General Hospital).

In 2008/09, five of the six adult transplant centres performed live kidney transplants. (Kingston was the exception although it performed four living kidney transplants in 2007/08.) Since live donor kidney transplants make up about half of the total number of kidney transplants, this helps reduce overall wait times. Figure 15 shows that in 2003, the wait times for deceased and live donor transplants combined was fairly similar in all five centres (about 3.8 years or 1,400 days). Deceased and live kidney donor transplant

[26] It is noted that the deceased donor rate can be influenced by a number of factors such as listing practices, public and provider attitudes toward transplantation, resource availability and other factors.

wait times are being compiled for 2006-2008. It is expected that the 2003 wait time profile has continued to 2008.

Figure 15: Kidney Transplant Waiting Times in Days (Living and Deceased Donors Combined) by Ontario Transplant Centre, 2001-2003



Source: Dr. J. David Russell (From Renal Transplant Working Group, Trillium Gift of Life Network, 2004. Analysis by Dr. Greg Knoll.)

Patients Waiting for a Liver

Individuals who received a liver transplant in Ontario from a deceased donor waited an average of 395 days in 2008 compared to 365 days in 2001 (Table 9).

Table 9: Wait Time of Patients Who Received Liver Transplants (Deceased Donors) in Ontario (Days), 2001-2008*

	2001	2002	2003	2004	2005	2006	2007	2008
Number of Patients	144	151	165	163	150	160	165	147
Average Wait in Days	365	339	366	371	338	342	393	395
Minimum-Maximum Wait in Days	0-2,110	0-1,711	0-2,355	0-3,669	1-3,524	1-1,891	1-3,208	2-2,768

Source: Trillium Gift of Life Network. Data extracted June 12, 2009 and provided by Jason Lian.
*Wait time is measured as the number of days between list date and the date of the liver transplant.

As with kidney, the wait time varied depending on the hospital where the deceased donor liver transplant was performed (Table 10). In 2008, patients waiting for a deceased donor liver waited an average of 371 days at UHN Toronto General compared to 421 days at London Health Sciences. The longest someone waited for a deceased donor liver at University Health Network was 5.4 years (1,977 days) compared to 4.8 years (1,765 days) at London Health Sciences.

Paediatric patients waited an average of 427 days in 2008 for a deceased donor liver with some waiting as long as 2,768 days (7.6 years).

Table 10: Wait Time of Patients Who Received Liver Transplants from Deceased Donors in Ontario (Days) by Hospital, 2006, 2007 and 2008*

Hospital	Number of Patients		
	2006	**2007**	**2008**
London Health Sciences: Children's Hospital of Western Ontario+		1	
The Hospital for Sick Children	12	13	11
London Health Sciences	51	59	59
UHN Toronto General	97	92	77
Total Number of Patients	**160**	**165**	**147**
	Average Wait in Days		
	2006	**2007**	**2008**
London Health Sciences: Children's Hospital of Western Ontario		2	
The Hospital for Sick Children	249	255	427
London Health Sciences	368	409	421
UHN Toronto General	340	406	371
Average Wait in Days Ontario	**342**	**393**	**395**
	Minimum-Maximum Wait in Days		
	2006	**2007**	**2008**
London Health Sciences: Children's Hospital of Western Ontario		2-2	
The Hospital for Sick Children	2-948	2-1,886	5-2,768
London Health Sciences	1-1,747	1-3,208	2-1,765
UHN Toronto General	1-1,891	2-2,534	2-1,977
Minimum-Maximum Wait in Days	**1-1,891**	**1-3,208**	**2-2,768**

Source: Trillium Gift of Life Network. Data extracted June 12, 2009 and provided by Jason Lian.
*Wait time is measured as the number of days between list date and the date of the liver transplant.
+All patients from London Health Sciences under the age of 18 have been re-assigned to the Children's Hospital of Western Ontario site. All patients from University Health Network were aged 18+. All patients from The Hospital for Sick Children were aged 0-17 years.

Patients Waiting for a Lung

Only two hospitals perform lung transplants in Ontario: The Hospital for Sick Children for paediatrics and UHN Toronto General for adults.

Individuals who received a lung transplant in Ontario from a deceased donor waited an average of 187 days in 2008 compared to 172 days in 2001 (Table 11). In 2008, some patients waited as long as three years for a lung transplant.

Table 11: Wait Time of Patients Who Received Lung Transplants (Deceased Donors) in Ontario (Days), 2006-2008*

	2006	2007	2008
Number of Patients	83	99	82
Average Wait in Days	172	130	187
Minimum-Maximum Wait in Days	7-1,447	1-1,253	3-1,134

Source: Trillium Gift of Life Network. Data extracted June 19, 2009 and provided by Keith Wong.
*Wait time is measured as the number of days between list date and the date of the lung transplant.

The Hospital for Sick Children performed less than five lung transplants each year from 2006 to 2008 (Table 12). UHN Toronto General performed 80 transplants in 2006, increased to 95 in 2007 and dropped to 78 transplants the following year. In 2008, adults waited an average of 193 days for a deceased donor lung with some patients waiting as long as three years. In 2008, the four paediatric patients waited 57 days on average with all the patients receiving their transplant within 174 days.

Table 12: Wait Time of Patients Who Received Lung Transplants from Deceased Donors in Ontario (Days) by Hospital, 2006, 2007 and 2008*

Hospital	Number of Patients		
	2006	2007	2008
The Hospital for Sick Children	3	4	4
UHN Toronto General	80	95	78
Total Number of Patients	**83**	**99**	**82**
	Average Wait in Days		
	2006	**2007**	**2008**
The Hospital for Sick Children	178	215	57
UHN Toronto General	171	127	193
Average Wait in Days Ontario	**172**	**130**	**187**
	Minimum-Maximum Wait in Days		
	2006	**2007**	**2008**
The Hospital for Sick Children	60-410	21-421	7-174
UHN Toronto General	7-1,447	1-1,253	3-1,134
Minimum-Maximum Wait in Days	**7-1,447**	**1-1,253**	**3-1,134**

Source: Trillium Gift of Life Network. Data extracted June 19, 2009 and provided by Keith Wong.
*Wait time is measured as the number of days between list date and the date of the lung transplant.

Patients Waiting for a Heart

Four hospitals perform heart transplants in Ontario. Paediatric patients go to The Hospital for Sick Children whereas adults can receive their transplant at London Health Sciences, The Ottawa Hospital (Ottawa Heart Institute) and UHN Toronto General.

Individuals who received a heart transplant in Ontario waited an average of 61 days in 2008 compared to 77 days in 2001 (Table 13). In 2008, some patients waited as long as 2.4 years for a heart transplant. This is a significantly shorter than in 2006 when some patients waited as long as four years to receive a heart transplant.

Table 13: Wait Time of Patients Who Received Heart Transplants in Ontario (Days), 2006-2008*

	2006	2007	2008
Number of Patients	77	71	61
Average Wait in Days	138	154	137
Minimum-Maximum Wait in Days	1-1,472	1-924	1-861

Source: Trillium Gift of Life Network. Data extracted June 19, 2009 and provided by Keith Wong.
*Wait time is measured as the number of days between list date and the date of the heart transplant.

The wait time varied depending on the hospital where the heart transplant was performed (Table 14). In 2008, adult patients waiting for a heart transplant waited an average of 121 days in London Health Sciences to 161 days at UHN Toronto General. The average wait at Ottawa Hospital was 154 days. The longest someone waited for a heart transplant at UHN Toronto was 2.4 years (861 days) compared to 1.9 years (678 days) at London Health Sciences and 1.8 years (552 days) in Ottawa .

Paediatric patients waited an average of 85 days in 2008 for a heart transplant with some waiting as long as 447 days (1.2 years).

Table 14: Wait Time of Patients Who Received Heart Transplants in Ontario (Days) by Hospital, 2006, 2007 and 2008*

Hospital	Number of Patients		
	2006	2007	2008
London Health Sciences	11	15	10
Ottawa Hospital (Ottawa Heart Institute)	14	14	12
The Hospital for Sick Children	20	18	13
UHN Toronto General	32	24	26
Total Number of Patients	**77**	**71**	**61**
	Average Wait in Days		
	2006	**2007**	**2008**
London Health Sciences	95	96	121
Ottawa Hospital (Ottawa Heart Institute)	147	268	154
The Hospital for Sick Children	77	102	85
UHN Toronto General	191	162	161
Average Wait in Days Ontario	138	154	137
	Minimum-Maximum Wait in Days		
	2006	**2007**	**2008**
London Health Sciences	1-385	1-488	3-678
Ottawa Hospital (Ottawa Heart Institute)	2-426	1-861	6-662
The Hospital for Sick Children	1-858	1-924	2-447
UHN Toronto General	3-1472	1-913	1-861
Minimum-Maximum Wait in Days	1-1,472	1-924	1-861

Source: Trillium Gift of Life Network. Data extracted June 19, 2009 and provided by Keith Wong.
*Wait time is measured as the number of days between list date and the date of the heart transplant.

Patients on a Transplant Wait List

There is some evidence to suggest that not everyone who could benefit from an organ transplant is put on an organ transplant list. Although it must be recognised that not everyone who is on dialysis is a suitable candidate for a transplant, only about 13% of people on dialysis in Ontario are on a kidney wait list (Table 15).

Table 15: Number of People on Dialysis and on Kidney Organ Wait Lists by Local Health Integration Network and Associated Transplant Centre, March 1, 2009

Local Health Integration Networks (LHINs) and Transplant Centre	Number of People on Dialysis	Number of People on Kidney Wait List	% of People on Dialysis Who are on the Kidney Wait List
Erie St. Clair, South West, and North East (.5) LHINs: London Transplant Centre	1,147	81	7.1%
Waterloo Wellington, and Hamilton Niagara Haldimand Brant LHINs: Hamilton Transplant Centre	1,407	203	14.4%
Central West, Mississauga Halton, Toronto Central, Central, Central East, North Simcoe Muskoka, North East (.5), Northwest LHINs: Toronto Transplant Centres	5,328	752	14.1%
South East LHIN: Kingston Transplant Centre	374	11	2.9%
Champlain LHIN: Ottawa Transplant Centre	934	151	16.2%
Ontario	**9,190**	**1,198**	**13%**

Source: Dr. Jeffrey Zaltzman, April 29, 2009.

Finally, people die waiting on organ transplant lists. It has been estimated that about 10% of people die waiting for a kidney, compared to 20-25% who die waiting for a liver or lung transplant. (In Toronto, 40-80 patients die waiting for a donated liver.)[27]

[27] Dr. Gary Levy, Verbal Communication, May 25, 2009.

8. TISSUE DONORS AND TRANSPLANTATION

This chapter presents:
- Tissue transplant services (8.1)
- Tissue donors, the demand for tissue, and cornea transplant wait times (8.2)

8.1 TISSUE TRANSPLANT SERVICES

Ontario has six tissue banks:
- Eye Bank of Canada - Ontario Division (Toronto)
- The Hospital for Sick Children Tissue Laboratory (Toronto)
- Ontario Professional Firefighters Skin Bank (Sunnybrook Health Sciences Centre, Toronto)
- Kingston General Hospital Bone Bank (Kingston)
- National Capital Region Bone Bank (Ottawa Hospital)
- Rubinoff Bone and Tissue Bank (Mount Sinai Hospital, Toronto)

Each of these tissue banks is governed and managed by separate organisations and is funded in different ways (e.g., cost recovery, fundraising, operating funds).

In addition to the six donation tissue banks, Ontario has as many as 15 hospital-based surgical bone banks with varying levels of activity. These banks maintain femoral heads recovered during total hip replacements for future use in orthopaedic surgery. As well, a surgical bone and deceased donation tissue bank has been developed in Thunder Bay with funding from a Northern Economic Initiative Grant. Known as The Lake Superior Centre for Regenerative Medicine, the organisation is interested in recovering and processing musculoskeletal tissue. It does not have approval to operate.

8.2 TISSUE DONORS, THE DEMAND FOR TISSUE AND CORNEA TRANSPLANT WAIT TIMES

Table 16 presents the tissue donors for transplantation, research and education in Ontario from April-January 2008/09. From 7,754 initial referrals for tissue, 874 donors gave eyes, one gave skin, 45 donated heart valves and 40 donated bone.

Table 16: Tissue Donors for Transplantation, Research and Education in Ontario, April-January 2008/09

Tissue Type	Referrals	Eligible Cases	Approaches	Consented Cases	Medically Suitable Cases	Donors
Ocular Tissue	7,754	7,240	3,426	1,038	984	874
Skin	7,754	3,592	2,319	273	170	1
Heart Valves	7,754	1,849	1,010	252	129	45
Bone	7,754	3,590	2,317	344	85	40

Source: Trillium Gift of Life Network

During this time period (April-January 2008/09), Trillium documented opportunities that were missed to donate tissue (Table 17). The major reason given for missed opportunities was lack of recovery resources.

Table 17: Missed Tissue Opportunities in Ontario, April-January 2008/09

Tissue Type	Missed	Reasons Given				
		Shortage Hospital Resources	Logistical Problems: Transport	Blocked by Coroner	Lack Recovery Resources	Other
Ocular Tissue	68	1	1	13	21	32
Skin	170	0	5	10	131	24
Heart Valves	81	0	1	21	10	49
Bone	44	1	1	17	5	20

Source: Trillium Gift of Life Network

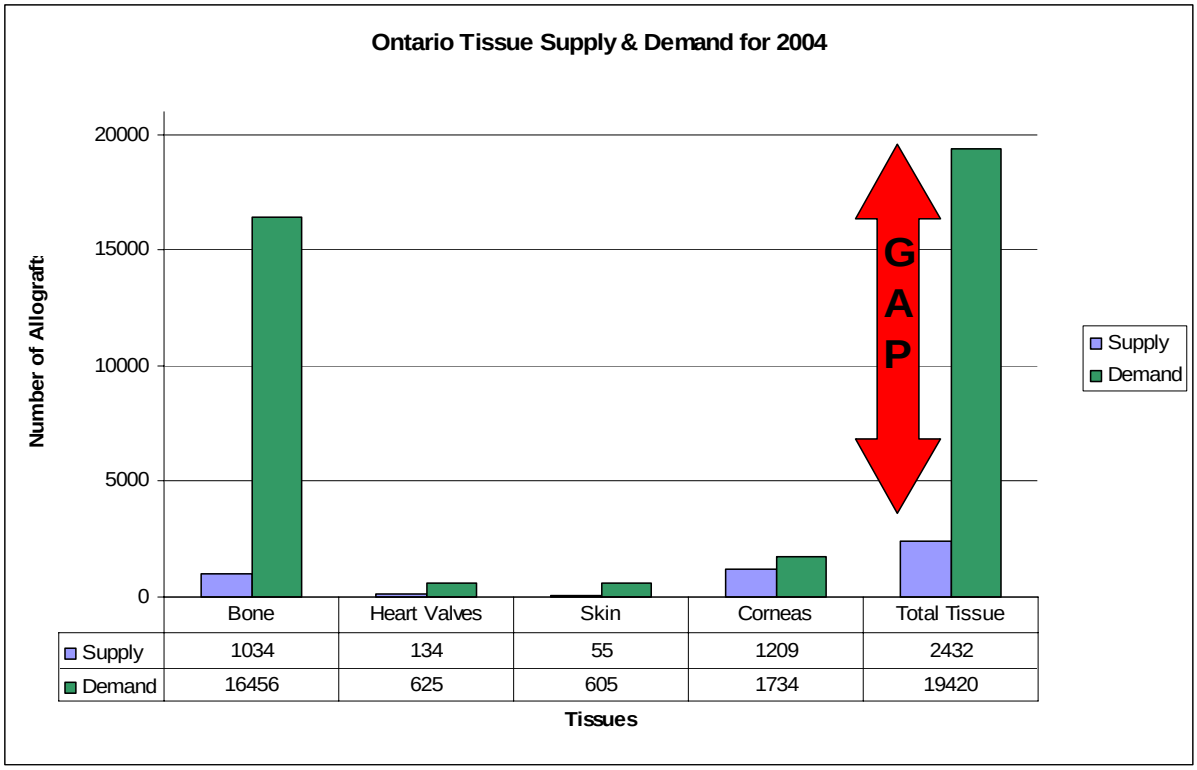
According to the Canadian Council on Donation and Transplantation, Ontario's demand for tissue in 2004 far exceeded the supply of tissue in the province (Figure 16). Ontario's tissue banks appear to be meeting less than 8% of the provincial demand for tissue. It has been estimated that hospitals and dental clinics meet the remaining demand by purchasing allografts from Canadian and American tissue banks at an estimated cost of about $19 million per year.[28] The majority of tissue products are purchased from large American not-for-profit and for-profit tissue banks.

Ontario's Wait Time Information System has been collecting wait times for cornea transplant since April 2007. Wait is measured as the time from the decision to have the transplant to the date of the procedure. The provincial Ophthalmology Expert Panel set the target wait time for cornea transplant at 182 days. In March 2009, the wait time in Ontario for cornea transplant was actually 459 days.[29] These waits have been steadily increasing.

[28] Trillium Gift of Life Network. 2006 (November 6). *Strategic Plan to Improve Tissue Donation Activities in Ontario*. Cost estimated using current supply data, CCDT demand data and average cost per graft.

[29] http://www.waittimes.net/waittimes/en/wt_data_map.aspx?LHIN=8&Mod=0. Accessed May 20, 2009.

Figure 16: Supply and Demand for Tissue in Ontario, 2004



Frank Markel, 2009 (May 4). "Performance Measures in Organ Donation in Ontario." Presentation at the Symposium: *Increasing Access and Reducing Wait Times for Transplantation in Ontario: The Path Forward*. Toronto, Ontario . Data from Canadian Council Donation & Transplant Demand for Human Allograft Tissue in Canada. Trillium obtained the data from the Ontario tissue banks.

9. FUNDING TO SUPPORT TRANSPLANTATION

The Ministry provides funds to support a number of transplantation efforts.

Trillium Gift of Life Network

Trillium is Ontario's central organ and tissue donation agency created by the Ontario Government in December 2000. The Ministry of Health and Long-Term Care funds Trillium to deliver on its mandate. Trillium's base and one-time funding from 2004/05 to 2008/09 is in Table 18. (Trillium's budget when it first began was about $7 million.)

Table 18: Trillium Gift of Life Network Budget, 2004/05-2008/09					
	2004/05	**2005/06**	**2006/07**	**2007/08**	**2008/09**
Total Base	$9,312,200	$11,729,050 *	$12,093,800 *	$13,695,900 +	$15,041,600 ~
One-Time	724,900	0	50,000	2,317,300	2,510,700
Total	**10,037,100**	**11,729,050**	**12,143,800**	**16,013,200**	**17,552,300**

Source: Ministry of Health and Long-Term Care.
*Includes $1.3 million to reimburse hospitals for deceased donor management activities administered by Trillium for the Ministry.
+Includes $1.9 million to reimburse hospitals for deceased donor activities and living donors for the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) administered by Trillium for the Ministry.
~ Includes $2.5 million to reimburse hospitals for deceased donor activities and living donors for the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) administered by Trillium for the Ministry.

Hospital Transplant Funding

The Ministry funds hospitals to perform organ transplants. The Transplant Working Group of the Joint Policy and Planning Committee (JPPC) developed the funding methodology for adult and paediatric organ transplants and procurement (and for bone marrow transplant) in September 1997.

Transplant Patient Expense Reimbursement Program

On April 20, 2009, the Minister of Health and Long-Term Care announced the launch of a fund beginning May 1, 2009 to reimburse transplant patients for limited accommodation-related expenses if the transplant hospital requires the transplant patient waiting for a heart, heart-lung or lung to relocate temporarily to the transplant hospital for a transplant.

The Transplant Patient Expense Reimbursement Program (TPER) reimburses qualified relocation accommodation expenses incurred as of May 1, 2009. The Ministry funds TPER and establishes policy and eligibility requirements; Trillium administers the program.

Program for Reimbursing Expenses of Living Organ Donors (PRELOD)

The Ontario Government established the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to reimburse eligible reasonable out-of-pocket expenses for costs incurred by potential and actual donors for travel, parking, meals, accommodation and loss of income. PRELOD is available to anyone in Ontario, out-of-province or out-of-country who donates or intends to donate an organ or part of an organ to an Ontario resident. The program was launched on April 1, 2008.

Deceased Organ Donation Funding to Hospitals

Trillium disburses funding to hospitals for deceased organ donation activities in accordance with a Ministry-approved funding methodology and rate. This funding recognises that hospitals have direct costs to support the deceased organ donation process.

Donor hospitals are reimbursed $6,000 to manage each deceased donor as follows: i) $800 for approaching the appropriate legal authority for consent (family/substitute decision maker); ii) $2,050 for medical testing; and iii) $3,150 for organ retrieval.

SECTION D: THE EXPERT PANEL'S DELIBERATIONS AND RECOMMENDATIONS

10. A PROVINCIAL INTEGRATED SYSTEM TO SUPPORT THE DONOR AND TRANSPLANT PATIENTS' JOURNEY

The Expert Panel was charged with developing a plan to provide Ontarians with equitable access to timely, appropriate and safe organ and tissue transplants. Recognising that many factors impact on successful organ and tissue transplantation, the Panel focused its deliberations on the system that needs to be in place to support the donor and transplant patients' journey. The expert panel did not address patient-specific factors that make a person a suitable candidate to donate or receive an organ or tissue. These factors have been well-researched and are documented in the scientific literature.

The *donor patient's journey* begins when the decision is made to donate an organ or tissue to a recipient (Figure 17). Living donors can donate a kidney, part of a liver, lung (lobe), small intestine and pancreas. Deceased donors can donate all these organs plus the heart and tissues. The living donor receives pre-donation care to maintain his or her health and well-being; the deceased donor usually receives pre-donation care to help maintain the quality of the organs and tissue being donated. Once the organ or tissue is donated, the living donor receives post-donation care.

The *transplant patient's journey* begins when the decision is made that a person needs a transplant. The patient receives pre-transplant care to help maintain his or her health and well-being to the highest extent possible. When an appropriate organ or tissue becomes available – and if the patient is still alive and remains a good transplant candidate – the patient receives the transplant and appropriate life-long post-transplant care.

A provincial integrated system to support the donor and transplant patients' journey has four main components that must effectively work together if Ontarians are to have equitable access to timely, appropriate and safe organ and tissue transplants (Figure 17). Not only do these components have to be integrated, each component has to work at a high level or else the system will only be as strong as the weakest link. These components are described briefly below and in more detail in the next four chapters.

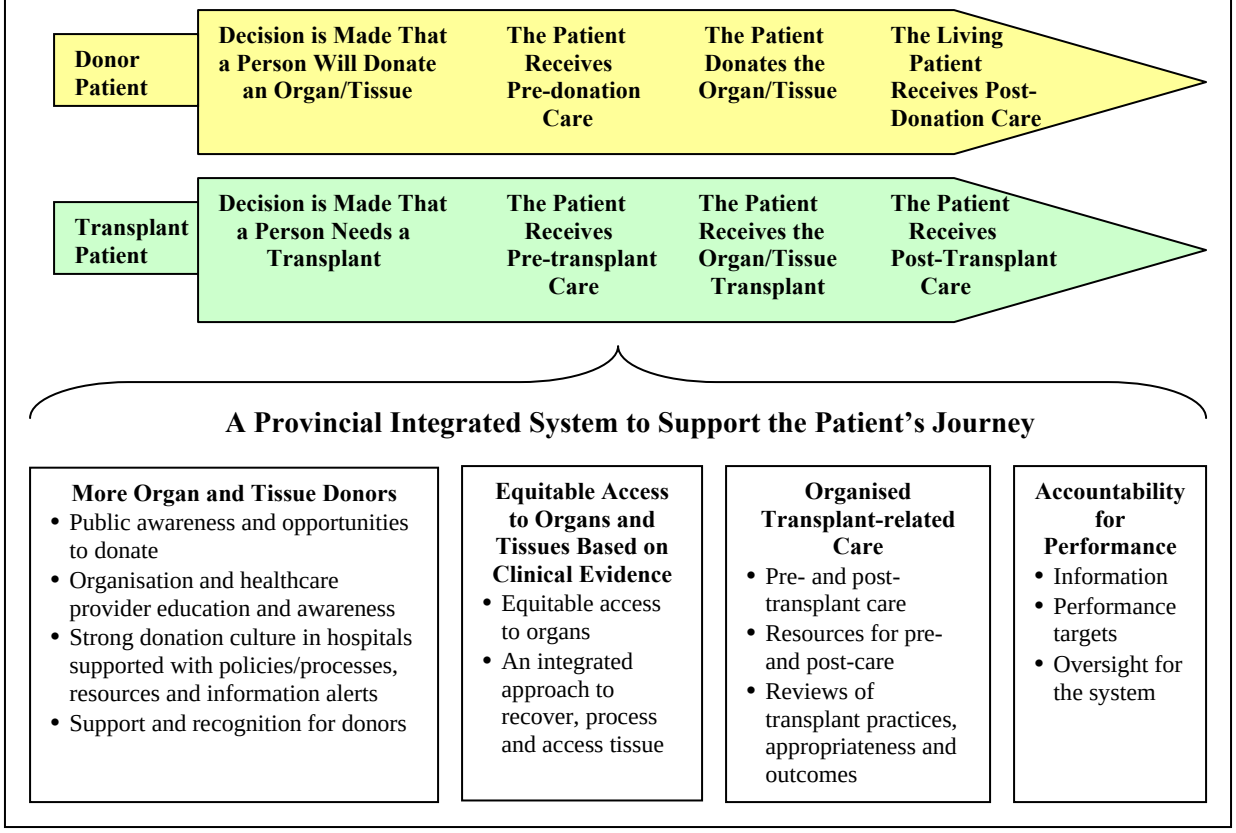
Component 1: More Organ and Tissue Donors

For Ontarians to expect that an organ or tissue will be available if they need it, comprehensive and sustained efforts must be made to get more organ and tissue donors. As one Panel member noted, "transplantation equals donation." This is a complex endeavour that involves the public, providers and policy makers, and includes:

- Public awareness and opportunities to donate;
- Organisation and healthcare provider education and awareness;

- Strong donation culture in hospitals supported with policies/processes, resources and information alerts; and
- Support and recognition for donors.

Figure 17: The Ontario Donor and Transplant Patients' Journey



Component 2: Equitable Access to Organs and Tissues Based on Clinical Evidence

Ontarians must be assured that they have equitable access to organ and tissue transplants based on clinical evidence. As part of Ontario's Wait Time Strategy, transplant must focus efforts on improving access to organs and tissues regardless of where one lives in the province.

Component 3: Organised Transplant-related Care

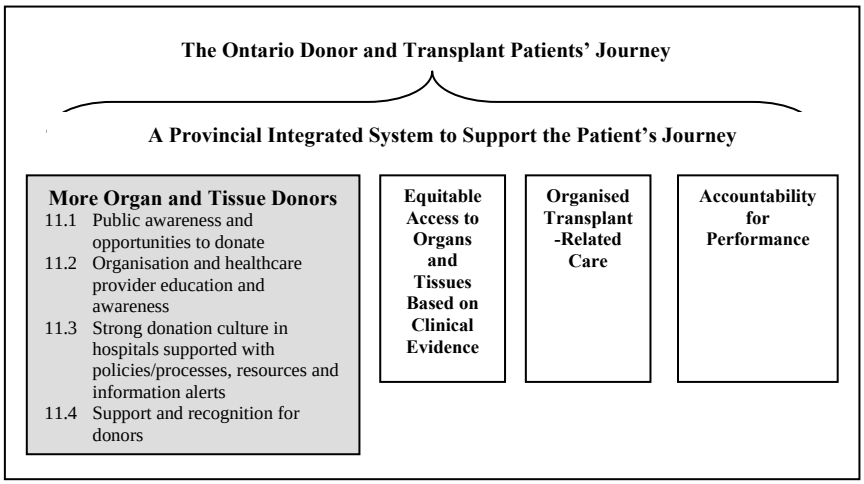
Individuals who need a transplant should have access to standard, best practice pre- and post-transplant care. Resources are required to support care. As well, transplant practices, appropriateness and outcomes need to be reviewed to ensure quality care.

Component 4: Accountability for Performance

It is imperative that everyone involved in supporting the donor and transplant patients' journey be held accountable for their performance. This requires an information system that is used to standardise and monitor activities, and performance targets that set out requirements for what each player is expected to accomplish. Oversight for the provincial integrated system is crucial to assure Ontarians that transplant will be a viable option for them if it is needed.

11. COMPONENT ONE: MORE ORGAN AND TISSUE DONORS

If a person in Ontario needs an organ transplant today, there is a very good chance that he or she will wait a long time with about 1,700 other people or die before an organ becomes available. The Panel believes that comprehensive and sustained efforts must be made to increase the number of organ and tissue donors in Ontario based on the following facts (see Chapters 7-8).



- Although the number of deceased and living organ donors in Ontario increased 55% between 1999 and 2008, this growth is not keeping up with the increasing population. When population growth is taken into account, Ontario's organ donation rate has remained the same over the last 10 years. Ontario's donation rate is below the Canadian average and is low compared to most other western countries.
- The largest increase in organ donations in this province has been due to more living donors. Between 1999 and 2008, the number of living donors increased 74% compared to a 32% increase in deceased donors. Although the increase in living donors is positive, there are risks to being a living donor.
- On May 27, 2009, 1,680 Ontarians were waiting for an organ. On average, Ontarians are likely to wait five years for a deceased donor kidney.
- People's health gets worse while waiting for a transplant. About 10% of people die waiting for a kidney, and 20-25% die waiting for a liver or lung transplant.
- With regard to tissue, the wait for a cornea transplant is about a year and a half. Access to other tissues is easier but costly. Currently, Ontario's tissue banks meet less than 8% of the provincial demand for tissue. Additional tissue is bought from Canadian and American tissue banks at about $19 million per year.

The Panel believes that the following initiatives will result in more organ and tissue donors in Ontario:

- Public awareness and opportunities to donate (11.1)
- Organisation and healthcare provider education and awareness (11.2)
- Strong donation culture in hospitals supported with policies/processes, resources and information alerts (11.3)
- Support and recognition for donors (11.4)

11.1 PUBLIC AWARENESS AND OPPORTUNITIES TO DONATE

The Panel believes that all Ontarians need to know that they have the right to donate their organs and tissues, and be provided with the option of donating the organs and tissues of their loved ones at the end of their lives.

Increasing public awareness about donation and providing opportunities to declare one's wish to donate will help increase the number of donated organs and tissues. Although telephone surveys indicate that there are high levels of public support for donation (82%),[30] this is not reflected in high numbers of donors. This contradiction highlights the need for effective *public awareness* initiatives supported with easily accessible and convenient *opportunities to donate* that use current technologies. These two areas are addressed below.

Public Awareness

One of Trillium's major activities is to increase public awareness about donation. According to the Ministry, about $1.7 million of Trillium's base budget is for communications which includes initiatives to increase public awareness about organ donation ($1.3 million). In addition, the Ministry has provided Trillium with funding for targeted public awareness initiatives. In addition to brochures, posters and various educational events, recent major public awareness initiatives on donation have included the following.

- The Ministry provided Trillium with $1.6 million in 2008/09 to implement the Organ Donation Strategy's Integrated Communications Plan.

- As part of the Organ Donation Strategy funding:
  - On April 20, 2009, Trillium launched a Youth Outreach website – *RecycleMe.org* – with supporting materials to increase awareness about organ and tissue donation among youth. (The Citizens Panel on Increasing Organ Donations recommended that Trillium develop a youth campaign on organ donation.[31])

[30] Trillium Gift of Life Network.

[31] The Citizens Panel on Increasing Organ Donations: Seeking views and opinions on increasing organ donations in Ontario (Chair, Ted Boadway), March 2007

- Trillium launched a Multi-Faith Outreach initiative that includes bi-annual multi-faith events across Ontario and faith-based donation brochures. In February 2009, culturally-specific brochures about organ and tissue donation for the Muslim and Jewish faiths and brochures in three First Nations languages were made available. (The Citizens Panel recommended that the Ontario government bring together a committee or conference of religious leaders to consider engaging religious schools in organ donation and implementing a program where religious communities observe a National Donor Sabbath in the same week every year.)

- *One Life … Many Gifts* is a public education program about donation and transplantation targeted at grade 11 students in Ontario. Developed as a partnership between London Health Sciences, the Kidney Foundation and Trillium, the pilot program first began in London area high schools in 2000. In 2008, a revised version of the program was piloted in 20 school boards across Ontario. The Panel supported additional funding for this program and was pleased that on April 20, 2009, the Ministry announced $185,000 in new funding to expand the *One Life … Many Gifts* curriculum in partnership with the Ministry of Education. The program will now be available in 326 secondary schools in Ontario.

In addition to Trillium's public awareness efforts, a number of non-profit organisations play a valuable role promoting and educating the public about organ donation. For example, the Kidney Foundation of Canada (Ontario) provides information on organ and tissue donation, and has annual Give the Gift of Life Walks in over 20 Ontario communities to raise funds and public awareness about kidney health, organ donation and living well with kidney disease.[32] Two more examples include the Canadian Liver Foundation which provides information on treatment for liver disease and transplantation,[33] and the Heart and Stroke Foundation of Ontario which provides information on heart health, heart disease and treatment including transplantation.[34]

In the Panel's view, many other public awareness initiatives on donation could be developed. For example, although Trillium has increased its community relations efforts with cultural and religious leaders, it needs to do more work finding leaders in various ethno-racial communities. The Panel recognises the importance of public awareness initiatives but is concerned that these could potentially be very expensive with limited results. Any additional initiatives to increase the public's awareness of donation and transplantation need to be strategic, make the most effective use of investments, and focus on achieving results. This could include:

- Conducting public awareness initiatives in collaboration with Government Ministries other than Health and Long-Term Care (e.g., Education; Training, Colleges and Universities; Health Promotion);
- Engaging innovative partners such as corporate sponsors;

[32] See http://www.kidney.on.ca/english.html.
[33] See http://www.liver.ca/Treatment_and_Transplantation/.
[34] See http://www.heartandstroke.on.ca.

- Using various communication methods; and
- Engaging and exploring the role of the Canadian Blood Services in public education and awareness. Part of the organ and tissue donation and transplantation mandate of the Canadian Blood Services includes support for the development, implementation and evaluation of leading practices including public education and awareness programs.[35]

The Panel believes that Trillium – in collaboration with donation and transplantation stakeholders – needs to develop a strategic marketing and education plan to increase the public's awareness of donation and transplantation, and build a donation culture where Ontarians believe that organ and tissue donation is part of the cultural fabric of this province. The plan should include a recommended course of action, clear deliverables, timelines and resource requirements.

The Panel recommends that:

R1 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a strategic marketing and education plan to increase public awareness of donation and transplantation, and build a donation culture where Ontarians believe that organ and tissue donation is part of the cultural fabric of this province. The plan should include a recommended course of action, clear deliverables, timelines and resource requirements.

To help inform efforts to get more Ontarians to donate organs and tissue, the Panel supports an epidemiological study of donors and the factors that impact on supporting living and deceased donation. As noted previously (Chapter 7), ethno-racial factors may impact on the decision to donate. Other factors could include gender, age, socio-economic status, education, religion, life experiences, level of altruism, and so on.

The Panel recommends that:

R2 Trillium Gift of Life Network – in consultation with donation and transplantation stakeholders – design and conduct an epidemiological study of donor characteristics that impact on supporting living and deceased donation. The study results should be used to inform efforts to increase organ and tissue donations in Ontario.

Opportunities to Donate

The method by which Ontarians can make their wish to donate known has evolved. Historically, people kept signed donor cards in their wallets and told their next of kin about their donation wishes. Ontarians could also mail in a donor registration form to the government to register their consent to donate, or register their consent in person when

[35] Letter of Intent dated March 31, 2008 Among Canadian Blood Services and the Provinces and Territories (excluding Quebec).

renewing or registering for a photo health card. As of December 1, 2008, only "yes" decisions to donate are being registered in the Ministry's database; as of July 1, 2009, Government will share "yes" decisions to donate with Trillium on an as needed basis.

The Panel believes that Ontarians should have easy and convenient opportunities to make their donation wishes known. The current methods do not take advantage of widely-used internet technologies. Online registrations are being used successfully in other jurisdictions such as British Columbia which allows online registration to legally record one's decision to donate.[36] Trillium has submitted a Business Case to the Minister of Health and Long-Term Care with recommendations to implement online donor registration. The Panel strongly supports this initiative.

The Panel recommends that:

R3 The Ministry of Health and Long-Term Care support the implementation of online registration to legally record one's decision to donate organs and tissue in Ontario. Traditional means of registering by mail and through the Service Ontario Health Card Offices (OHIP) should continue.

11.2 ORGANISATION AND HEALTHCARE PROVIDER EDUCATION AND AWARENESS

Organisation and healthcare provider education and awareness will help increase organ and tissue donations in Ontario. Although Trillium distributes posters and brochures to physician offices and various public places, this is a passive method of raising awareness and promoting donation. The impact of this approach is also unclear. The Panel believes that an *active and collaborative approach* is needed to increase awareness of donation and transplantation among organisations and healthcare providers. This approach needs to be planned carefully and include tactics and information specific to each group at various points in the career lifecycle.

Education and awareness efforts ***targeted at organisations*** need to include hospitals, community care access centres, community-based agencies, ambulance services, and companies that interact with the public on death-related issues such as law offices, insurance companies, funeral planners and coroners' offices. Education and awareness efforts ***targeted at healthcare providers*** need to include the full range of general and specialty care including medical specialists, physicians, nurses, paramedics, pharmacists, and others.

Provider education and awareness must begin with the *initial training* of healthcare providers. Currently, most students receive little formal education on donation and transplantation. For example, emergency physician training in Ontario does not appear to include organ donation, donation after cardiac death or tissue retrieval as a topic in

[36] See https://www.transplant.bc.ca/onlinereg/bcts.asp.

residency core rounds/seminars.[37] As well, the major emergency medicine textbooks and journals include little information on donation. Trillium has proposed to the Royal College of Physicians and Surgeons' Office of Education that a standard donation education curriculum be developed and implemented in every emergency room and intensive care training program in Canadian academic centres. Recognising that individual specialties will need to support the idea, the intention is that residents will be exposed to the standards of diagnosis and support for organ donors and their families. Ideally, this curriculum should be extended to other healthcare professionals.

In addition to the initial training of healthcare providers, education and awareness of donation and transplantation need to be *part of the continuing education* of healthcare providers working in the system. It is critically important that healthcare providers be able to identify donation potential and support the donation process. This awareness goes beyond the intensivists and medical/hospital staff working in critical care and emergency departments to include medical and hospital staff working on in-patient units throughout the hospital. A number of Panel members believe that opportunities for Donation After Cardiocirculatory Death (DCD) are being missed due to lack of knowledge and clinical triggers for DCD in teaching and community hospitals. Trillium will begin hosting provincial donation rounds through the Ontario Telemedicine Network in July 2009. Strategic efforts to increase education and awareness of donation potential among organisations and healthcare providers need to be on a number of levels

At the provincial level, Trillium should collaborate with the donation and transplantation community, organisations, professional associations and regulatory colleges to increase donation awareness among organisations and healthcare providers and their clients and patients. These groups include – but are not limited to – the Ontario Hospital Association; clinical sections of the Ontario Medical Association; professional regulatory colleges such as the College of Physicians and Surgeons of Ontario, the Ontario College of Family Physicians, College of Nurses of Ontario, Ontario College of Pharmacists and others; medical schools; Emergency Medical Services; Ontario's Critical Care Secretariat; Ontario's Neurosurgery Expert Panel; Ontario's primary health care groups and teams; the Law Society of Upper Canada; insurance associations; and others. Innovative ways to increase awareness should be explored. For example, Trillium and the transplantation community could develop education programs in partnership with the professional regulatory colleges that could be recognised as continuing education credits for recertification.

At the regional level, each Local Health Integration Network (LHIN) or groups of LHINs should promote education about donation. Currently, each LHIN has designated Critical Care and Emergency Room LHIN Leads who focus on improving access to these services. There may be opportunities for these formal groups – in consultation with Trillium and the transplantation community – to promote education on donation among their colleagues.

[37] Michael Schull. 2009 (May 4). "The Emergency Department Perspective" Presentation at the Symposium: *Increasing Access and Reducing Wait Times for Transplantation in Ontario: The Path Forward*. Toronto, Ontario.

At the local level, Trillium should work with the donation and transplantation communities to document donation best practices, identify organisations that use these best practices, develop a best practices checklist to be used by underperforming hospitals to monitor and improve their performance, and promote the use of best practices in underperforming sites (e.g., coaching teams, individual hospital site visits, LHIN-based education sessions, videoconference education sessions, etc.).

The Panel recognises that many initiatives could be launched to increase organisation and healthcare provider awareness. As with public awareness, organisation and provider awareness initiatives are critically important but could potentially be very expensive with limited results. The Panel believes that these initiatives need to be strategic, make the most effective use of investments, and focus on achieving results. Trillium should collaborate with the donation and transplantation communities to develop a plan to increase organisation and healthcare provider awareness about donation. The plan should actively engage the participation of others, and Trillium should facilitate the implementation of the plan.

The Panel recommends that:

R4 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a comprehensive organisation and healthcare provider awareness and education plan to increase awareness about organ and tissue donation. The plan should identify provincial, regional and local solutions to increase education and awareness, and actively engage the participation of organisations, professional associations, health regulatory colleges, and other groups (e.g., Ontario's Critical Care Secretariat and Neurosurgery Expert Panel). Furthermore, the plan should incorporate innovative ways to promote donation awareness (e.g., develop education programs in partnership with the health regulatory colleges that would recognise the programs as continuing education credits for professional recertification). Trillium should facilitate the implementation of the plan to help raise awareness of donation and transplantation among organisations and healthcare providers, and their clients and patients.

11.3 STRONG DONATION CULTURE IN HOSPITALS SUPPORTED WITH POLICIES/PROCESSES, RESOURCES AND INFORMATION ALERTS

A strong donation culture in hospitals is critical for increasing organ and tissue donations. Hospital and medical leaders who are strongly committed to donation are needed to create and sustain such a culture. Although donation leadership needs to exist throughout the hospital in emergency departments, critical care units, neurosurgical units and inpatient wards, the Panel believes that hospitals in Ontario with Level 3 critical care units should identify a donation champion who is responsible for working with others to

sustain a strong donation culture.[38] The champion should be a well respected physician leader who works closely with the hospital's donation coordinator, if available.

The Panel recommends that:

R5 Ontario hospitals with Level 3 critical care units identify a donation champion who is responsible for working with others to sustain a strong donation culture in the organisation. The champion should be a well respected physician leader who works closely with the hospital's donation coordinator, if available.

The donation culture should be supported by:
- Policies and Processes;
- Resources; and
- Information Alerts.

These supports are addressed below.

Policies and Processes

The *first element of a strong donation culture in hospitals* is targeted policies and processes. The Panel identified four areas in particular where policies and processes are needed:
- Organ and Tissue Donation Committee
- Requirement to Notify Trillium Gift of Life Network
- Standard Policies for Donation After Neurological or Cardiocirculatory Death
- Organ and Tissue Donation as Part of End-of-Life Policies in Critical Care, Emergency Care and Neurosurgical/Neurological Care

Organ and Tissue Donation Committee

All Ontario hospitals with Level 3 critical care units should have an Organ and Tissue Donation Committee to oversee all donation-related activities (see Appendix 4 for the levels of critical care). The Committee should promote awareness of organ and tissue donation in the hospital; develop, implement and monitor organ and tissue donation protocols; ensure that regular professional education on donation is provided in the

[38] A Level 3 critical care unit is capable of providing the highest level of service to meet the needs of patients who require advanced or prolonged respiratory support, or basic respiratory support together with the support of more than one organ system. This is generally considered a "full service" Critical Care unit even though some specialized services may not be available (e.g., dialysis). All Level 3 units are capable of invasive ventilatory support. See Appendix 4 for the levels of critical care.

hospital; and set performance targets and accountabilities for donation.[39] It is noted that 76 hospitals in Ontario reported having one or more Level 3 critical care units.[40]

The Panel recommends that:

R6 Ontario hospitals with Level 3 critical care units be required to establish and operate an Organ and Tissue Donation Committee.

Requirement to Notify Trillium Gift of Life Network

The *Trillium Gift of Life Network Act* requires designated facilities to notify Trillium as soon as possible when a patient at the hospital has died or a physician is of the opinion that the death of a patient at the facility is imminent by reason of injury or disease (8.1.1). A designated facility is not required to notify Trillium if it has identified circumstances in which notice is not required (8.1.2).

Currently, Trillium only requires 21 Tier 1 hospitals to notify it when a patient has died (see Appendix 4 for the Tier 1 hospitals). In the Panel's opinion, notifying Trillium after death has occurred may not enable hospitals to identify and capture all donation opportunities. The Panel believes that Trillium should be notified ***after*** the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies ***and before*** the withdrawal of these therapies has begun.[41] Sufficient time should be available for Trillium to dispatch a coordinator to the hospital to work with the clinical team on a plan to approach the family/substitute decision maker. Furthermore, the Panel believes that all 76 hospitals in Ontario with Level 3 critical care units should be required to notify Trillium. All these hospitals are capable of providing the highest level of service to meet the needs of patients who require advanced or prolonged respiratory support, or basic respiratory support and the support of more than one organ system.

The Panel recommends that:

R7 Ontario hospitals with Level 3 critical care units be required to notify Trillium Gift of Life Network *after* the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies *and before* the withdrawal of these therapies has begun.

[39] The Panel notes that that Committee can be formally required under the *Trillium Gift of Life Network Act*: 8.3(1): which states that: a designated facility shall establish such committees as may be prescribed by the Minister, and the duties of the committees shall include such matters as the Minister may prescribe. 2000, c. 39, s. 4.).

[40] Ontario Critical Care LHIN Leadership Table. nd. *Inventory of Critical Care Services: An Analysis of LHIN-Level Capabilities.* Note: The inventory was completed from June to September 2006.

[41] This requirement can be made under the *Trillium Gift of Life Network Act* – 8.1.3: the designated facility shall give a notice in accordance with such requirements as may be established by the Network and the notice must include the information required by the Network.

Standard Policies for Donation After Neurological or Cardiocirculatory Death

Hospitals with Level 3 critical care units should have guidelines for the withdrawal of life-sustaining therapies. These guidelines should focus on the best interests of patients and their families, and not be influenced by donation potential. In addition, these hospitals should adopt standard policies for *Donation After Neurological Death*, and for *Donation After Cardiocirculatory Death* that are consistent with those established by the Canadian Council for Donation and Transplantation Consensus Conference, and adapted by Trillium Gift of Life. These policies can be used without compromising the optimal treatment of the patient and the family.

There seems to be good support in Ontario for Donation after Cardiocirculatory Death (DCD). However, there may be ideological issues with promoting DCD among physicians who are uncomfortable with the practice. Although there is a need to respect physician discomfort with DCD, this should not be a deterrent for DCD to occur.

The Critical Care Leads for each Local Health Integration Network (LHIN) should ensure that the hospitals within their respective LHIN have adopted these guidelines and policies, and use them to guide their clinical practice.

The Panel recommends that:

R8 **Ontario hospitals with Level 3 critical care units adopt standard policies for *Donation After Neurological Death*, and for *Donation After Cardiocirculatory Death* that are consistent with those established by the Canadian Council for Donation and Transplantation Consensus Conference and adapted by Trillium Gift of Life Network. The Critical Care Leads for each Local Health Integration Network should ensure that the hospitals within their respective LHINs adopt these policies and use them to guide their clinical practice.**

Organ and Tissue Donation as Part of End-of-Life Policies in Critical Care, Emergency Care and Neurosurgical/Neurological Care

End-of-life care is provided to people in their final stages of life. In the Panel's view, organ and tissue donation needs to be integrated into end-of-life policies in critical care, emergency care and neurosurgical/neurological care.

At the ***provincial level***, organ and tissue donation should be reflected in Ontario's Critical Care Strategy (through the Critical Care Secretariat), the Emergency Room Strategy (through the ER/Alternate Level of Care Expert Panel), and the Neurosurgery Strategy (through the Neurosurgery Expert Panel). At the level of the ***Local Health Integration Network***, each LHIN has critical care leads and emergency room leads who should promote and support organ and tissue donation in hospital critical care units and emergency departments as part of end-of-life care.

The Panel recommends that:

R9 Ontario's Critical Care Secretariat, the Neurosurgery Expert Panel, and the Emergency Room/Alternate Level of Care Expert Panel integrate organ and tissue donation as part of end-of-life care in their respective strategic areas. In addition, the Local Health Integration Network (LHIN) Critical Care Leads and Emergency Room Leads should promote and support organ and tissue donation in critical care units and emergency departments, in their respective LHINs, as part of end-of-life care.

Resources

The *second element of a strong donation culture in hospitals* is sufficient resources to support many donations. Human, and capital and operating resources are addressed below.

Human Resources: Donation Coordinators and Tissue Donor Consent and Screening

Trillium funds 21 donation coordinators in Tier 1 hospitals who are trained to speak with donor families and obtain consent (see Appendix 4 for the Tier 1 hospitals). The coordinators are registered nurses with critical care training who are paid at the staff RN level. The three main roles of the coordinators are: i) having discussions with the family and obtaining consent; ii) supporting donor management which includes acting as a nursing resource to the critical care physician; and iii) developing the hospital's donor program. Increasingly, donation coordinators are leaving these positions to work in the hospital at a higher pay scale. Trillium is reviewing the role and its responsibilities and compensation.

A recent review of 20 observational studies and audits found that using trained and experienced individuals to make a request for organ donation was one of two factors that had the largest effect on organ consent rates (the other factor was the timing of the conversation).[42]

The Panel recognises the importance of the donor coordinator program and supports the need for a stable infrastructure of coordinators in Ontario. It is expected that more donor opportunities will be identified in hospitals that do not have on-site donor coordinators. For example, Recommendation 7 requires the 76 Ontario hospitals with Level 3 critical care units to notify Trillium *after* the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies *and before* the withdrawal of these therapies has begun. Although it is unrealistic to expect

[42] Simpkin, AL., LC Robertson, VS Barber, JD Young. 2009. "Modifiable factors influencing relatives' decision to offer organ donation: systematic review" *British Medical Journal*: 339:b1991doi:10.1136/bmj.b991.

that each of these hospitals will have a donor coordinator on site, the need for support provided by donor coordinators will be critical.

The Panel recommends that:

R10 The Ministry of Health and Long-Term Care continue to fund Trillium Gift of Life Network for the donor coordinator program, assess the adequacy of the current level of support, and make any necessary adjustments.

The Ministry provided Trillium with one-time funding of $936,700 in 2007/08 and $910,700 in 2008/2009 to support tissue donor consent and screening. Current funding is not part of Trillium's ongoing base budget. According to Trillium, these funds have resulted in a 22% increase in tissue donation.

The clinical services team in Trillium's Provincial Resource Centre call families to discuss the option of donating the tissue of a loved one. A review of calls made to families from September 2008 to March 2009 found that telephone consent and screening produced better donation results than in-hospital face-to-face interactions with healthcare professionals (49% consent compared to 16%). The program appears to be popular with hospital staff whose time is freed up to provide other care. Currently, only families of patients in intensive care units in selected hospitals are approached. It may be possible to get quality tissue on other patient care areas.

The Panel recommends that:

R11 The Ministry of Health and Long-Term Care provide ongoing base funding to Trillium Gift of Life Network to support tissue donor consent and screening.

Capital and Operating Resources

It is unclear how many donations are lost due to the lack of staffed operating rooms to retrieve organs. The donor hospital uses a lot of time and resources to support a donor before the organs can be retrieved. Donor hospitals are required to supply the operating room, surgical nurses, anaesthetist and any other required operating room staff.

It is unclear exactly how many donations are lost due to the lack of critical care beds to support the organ donor and recipient. Critical care is an important link for identifying potential donors with severe acquired brain injury or opportunities for donation after cardiocirculatory death. Critical care is also needed to support the transplant patient. In 2006, the Ministry launched the provincial Critical Care Strategy which includes the critical care information system. All Level 3 adult medical/surgical intensive care units across 65 hospital corporations report data on beds, admitted critical care patients, interventions performed to address care needs, and the use of Critical Care Response

Teams. Currently, no hospital in Ontario has staffed critical care beds solely designated for donation and transplantation.

In the Panel's view, the Critical Care Secretariat should ensure that sufficient critical care resources – which include staffed beds – are in place to support donation and transplantation. The Secretariat should identify those facilities that would benefit most from critical care capital and operating resources to support donation. In fact, support for donation should be one criterion used to allocate additional critical care resources. This will especially be important to meet the resource needs of more organ and tissue donors in the province.

The Panel recommends that:

R12 The Critical Care Secretariat of the Ministry of Health and Long-Term Care assess the critical care bed supply in the province to identify facilities that would benefit most from critical care resources to support organ and tissue donation. This should be one criterion used to allocate additional critical care capital and operating resources in the future.

Every hospital in Ontario should support donation as a natural part of end-of-life care. Donation is a rare event that requires a quick response and resources that must be galvanized quickly. Hospitals need to be adequately remunerated to cover their costs.

In July 1998, the Joint Policy and Planning Committee developed the funding methodology for adult and paediatric organ transplants and procurement (and for bone marrow transplant).[43] In the Panel's view, the Ministry should conduct an updated review of the payment schedule for donation and transplantation. Having said that, hospitals need to recognise that organ retrieval is an organisational priority and should re-allocate hospital resources to support retrieval, when required. Physician compensation should also be reviewed within the current Ontario Medical Association funding envelope.

The Panel recommends that:

R13 The Ministry of Health and Long-Term Care review the payment schedule for organ and tissue donation and transplantation to ensure that hospitals are adequately compensated for the costs of supporting these activities. In addition, the Ministry should review physician compensation within the current Ontario Medical Association funding envelope.

[43] Joint Policy and Planning Committee Transplantation Working Group. 1998 (July). *A Methodology for Costing and an Approach for Funding Transplantation: Final Report*. Reference Document #RD 7-2.

Information Alerts

The *final element of a strong donation culture in hospitals* is information alerts. A number of information systems have been or are in the process of being developed that can help identify potential donors in hospital. These systems include:

- The Critical Care Information System downloads patient information twice daily from all Level 3 adult medical/surgical intensive care units across 65 hospital corporations in Ontario.
- CritiCall is the 24-hour medical emergency referral service for hospital-based physicians in Ontario. CritiCall is aware of all critically ill patients who may require an assessment and transfer to more specialised facilities for ongoing treatment.
- The Emergency Neurosurgery Image Transfer System will enable CT images to be viewed remotely anywhere in the province by neurosurgeons for the purposes of consultation. More comprehensive and timely consultations will be provided and unnecessary patient transfers to neurosurgical centres reduced. A total of 130 hospital sites will be using the system by August 31, 2009. This work is being done under the guidance of the provincial Neurosurgery Expert Panel (chaired by Dr. James Rutka).

The Emergency Neurosurgery Image Transfer System (ENITS) is especially important for identifying potential donors who have suffered severe neurological damage. In the past, neurosurgical units tended to accept the transfers of all patients with severe neurological damage including those who had very little chance of survival. If these patients did not survive, they were considered as potential donors. Two significant changes have occurred in healthcare practice. One, with limited neurosurgical capacity, it is unlikely that patients will be accepted for transfer to a neurosurgical centre unless there is a reasonable chance of success after surgery. Two, with the introduction of ENITS, neurosurgeons in neurosurgical centres will be able to provide a consultation and assess patients remotely with greater accuracy. This means that critically ill patients who were transferred to specialised centres in the past and became donors, may remain in their local community hospitals. This has the potential of decreasing the number of organ donors in Ontario unless these individuals are identified are donation opportunities. Neurosurgeons who view ENITS should connect with Trillium to identify these opportunities. This will strengthen the link with neurosurgery and identify organ potential.

The Panel recommends that:

R14 The Critical Care Secretariat and the Neurosurgery Expert Panel work with Trillium Gift of Life Network to ensure that the Critical Care Information System, CritiCall, and the Emergency Neurosurgery Image Transfer System be used as tools to provide appropriate alerts to Trillium to enable the agency to evaluate the potential for donation. In particular, neurosurgeons who are viewing the Emergency Neurosurgery Image Transfer System should be required to contact Trillium when potential donation opportunities arise.

11.4 SUPPORT AND RECOGNITION FOR DONORS

The final initiative to get more organ and tissue donors is support and recognition for donors.

Providing support for living donors can help increase organ donations. In the past, Ontarians faced numerous disincentives to becoming living donors. Donors had to pay for the costs related to donating an organ such as travel, accommodation, meals, child care, post-hospital care, medical expenses, drugs, costs of psycho-social adjustment and rehabilitation. Donors also faced lost wages by missing work to recuperate after surgery, and were not legally protected from losing their jobs.

In 2000, the Premier's Advisory Board recommended that living donors be eligible for unemployment insurance. In 2007, the Citizens Panel recommended that the Ontario Government enact legislation to ensure living donors are guaranteed job security and that a fund be established to pay for reasonable pre-approved expenses and lost wages.

The Panel is pleased that the Ministry has addressed these recommendations with a number of initiatives:

- On April 1, 2008, Trillium launched the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to help assist potential and actual living donors for: i) out-of-pocket expenses for travel, accommodations, parking, meals, and meal allowance during assessment and immediate post-surgery period; and ii) loss of income subsidy for persons who will be off work following surgery and during their recovery period (up to a maximum of $400 or 55% of net earnings per week for an eight week period using a deductive process after all other sources of income are exhausted). The program was retroactive for expenses incurred from August 3, 2007.

- On March 2, 2009, Government announced that it was introducing a job protection leave bill for living organ donors. The bill – which received 3rd reading on May 27, 2009 and Royal Assent on June 5, 2009 – will amend the *Employment Standards Act, 2000* to provide unpaid job-protected leave for employees who donate certain organs to another individual (all or part of a kidney, liver, lung, pancreas and/or small bowel). It is anticipated that the bill will be proclaimed on June 29, 2009.

The eligibility and claim conditions for PRELOD are quite limiting. For example, travel subsidies are only provided if the donor lives 60 km or more one-way from the transplant hospital (for land travel) even though all donors incur travel costs. As well, $125 per night is provided for accommodation (up to $625) if a living donor lives 100 km or more from the transplant hospital. The maximum amount for accommodation is insufficient for donors who must stay close to the transplant hospital for longer periods of time. The Panel believes that efforts should be made to enhance PRELOD, where possible, given that the program is used to support people who are donating their organs.

The Panel recommends that:

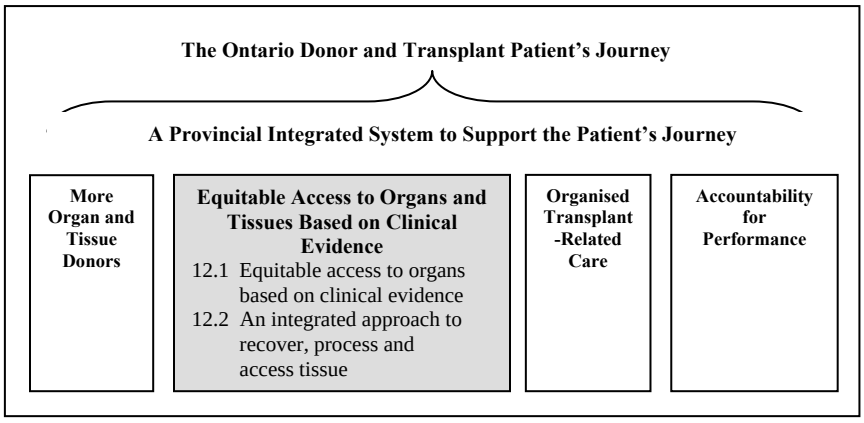
R15 The Ministry of Health and Long-Term Care – in collaboration with Trillium Gift of Life Network and living donors – identify ways to enhance the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to support potential and actual living donors.

Finally, recognition for deceased and living donors may help encourage more organ and tissue donations. Currently, Trillium has a recognition event for deceased donors only. Some of the transplant programs have recognition events for living donors. The Panel supports a consistent provincial approach for recognising deceased and living donors.

The Panel recommends that:

R16 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a provincial program that recognises all deceased and living organ and tissue donors in Ontario.

12. COMPONENT TWO: EQUITABLE ACCESS TO ORGANS AND TISSUES BASED ON CLINICAL EVIDENCE



Many people are on organ waiting lists in Ontario. If someone needs an organ transplant, the time he or she will wait depends on when a suitable organ becomes available and where. Access to organs varies across the province for a number of reasons. The panel believes that equitable access to organs and tissues based on clinical evidence must be put in place based on the following facts (Chapters 7-8).

- Deceased organ donation rates range widely from a low of 10.4 per million population in the Toronto region to a high of 24.9 per million in London.
- Wait times vary by transplant centre. Someone waiting for a deceased donor kidney can expect a median wait time of 2.5 years in London compared to 6.9 years in Toronto at St. Michael's. The difference in wait times for deceased donor kidney transplants appears to depend mainly on the deceased donor rate in each region.
- Wait times for live donor transplants are generally less than for deceased donor transplants which reduces overall wait times. However, not everyone will have access to a live donor organ.
- Ontario's tissue banks are meeting less than 8% of the provincial demand for tissue. The rest of the demand is met by purchasing tissue outside of the province.

The Panel supports the following initiatives:
- Equitable access to organs based on clinical evidence (12.1)
- An integrated approach to recover, process and access tissue (12.2)

12.1 EQUITABLE ACCESS TO ORGANS BASED ON CLINICAL EVIDENCE

There is the *perception* that there is inequitable access to transplant organs in Ontario. A number of factors contribute to this view.

One, deceased organ donation rates in Ontario range widely from a low of 10.4 per million in the Toronto region to a high of 24.9 per million in London (Figure 2). Although Trillium primarily focuses its efforts on increasing the number of deceased donors, the significant variation in donation rates across the province suggests that certain areas have stronger and more successful donation cultures for deceased donors.

Two, deceased organ donation rates have a direct impact on access and wait times for transplant procedures. Generally, the more organs available to the population, the lower the wait times. Someone waiting for a deceased donor kidney can expect a median wait time of 2.5 years in London compared to 6.9 years in Toronto at St. Michael's. Organs from living donors help to decrease overall wait times. The fact that living donor kidney transplants make up about half of all kidney transplants in Ontario means that the wait time for a kidney transplant (deceased and living donors combined) is fairly similar in the five major transplant centres: about 3.8 years in 2004 (see Chapter 7).

Three, although Trillium has a registry of all persons who are waiting for an organ transplant, regional lists for some organs are kept for *adults* due to historical practice patterns and partnerships. The allocation methods for organs are as follows.

- ***Hearts and lungs*** are allocated to adults and paediatrics using one provincial list for each of these two organs. For adult and paediatric hearts, there is national organ sharing for the highest status patients. A heart retrieved from a paediatric organ

donor is allocated to a paediatric heart candidate (i.e., less than 18 years old at the time of listing) before the heart is offered to an adult.

- ***Livers*** are allocated to the two liver centres (London Health Sciences and University Health Network) using two regional allocation lists for both adult and paediatric patients. Livers from paediatric donors are allocated to paediatric recipients before they are offered to an adult.
- ***Adult kidneys*** are allocated to the six kidney transplant centres using five regional allocation lists (expressed by Local Health Integration Network or LHINs):
  - Erie St. Clair, South West, and North East (.5) LHINs: London Health Sciences
  - Waterloo Wellington, and Hamilton Niagara Haldimand Brant LHINs: St. Joseph's Hamilton
  - Central West, Mississauga Halton, Toronto Central, Central, Central East, North Simcoe Muskoka, North East (.5), Northwest LHINs: University Health Network, St. Michael's
  - South East LHIN: Kingston General
  - Champlain LHIN: The Ottawa Hospital
- ***Paediatric kidneys*** are allocated to paediatric candidates before being offered to an adult. There is predominantly one provincial centre for paediatric kidney transplantation.

It is noted that there are no transplant centres in Northern Ontario.

The *perception* of inequitable access to transplant organs in Ontario tends to centre on the regional allocation lists for deceased donor livers and kidneys. In reality, the wait time for *deceased donor liver* transplants in adults is fairly similar at London Health Sciences and UHN Toronto General (see Table 10). The median wait time for *deceased donor kidney* transplants varies significantly by hospital from 2.5 to 6 years, as noted above. When living kidney donations are included, kidney wait times are fairly similar in all five centres (see Figure 15). The major issue with living donation – in addition to the risks to the donor – is that not everyone has an equal chance of accessing a live donor kidney.

Access to organs is a significant problem for Ontarians and wait times continue to be unacceptably long. Although the Panel supports equitable access to organs, unless the number of deceased organ donors is also increased, the overall situation will not improve. A concerted effort must be made by Trillium, the transplant centres and all donor hospitals to increase the number of deceased organ donors in the province, and reduce the disparities in the rate of deceased organ donations across the regions. The Panel has made 16 recommendations to help increase the number of organ and tissue donors in Ontario (see Chapter 11).

The need for a provincial allocation system for all deceased organs has been discussed for quite some time. In May 2000, the Advisory Board on Organ and Tissue Donation recommended that the new provincial organ procurement organisation (which became Trillium Gift of Life Network) manage transplant waiting lists.[44] One of Trillium's

[44] *A Plan for Change and Action. Report of Premier Harris' Advisory Board on Organ and Tissue Donation* (Chair, Don Cherry), May 2000.

objects – as noted in the *Trillium Gift of Life Network Act* – is "to establish and manage waiting lists for the transplant of tissue and to establish and manage a system to fairly allocate tissue that is available." Such a system has not been developed.

The Panel debated the benefits and limitations of a single provincial allocation system for deceased organs (kidneys, livers, kidney-and-pancreas). All members agree that access to and wait times for deceased organ transplants will only improve if Ontario's deceased organ donation rate increases. There was further agreement that deceased organ donation rates need to be equally high in all regions across the province. An epidemiological study of donor characteristics (Recommendation 2) will provide some insights into regional disparities as will an assessment of other contributing factors.

Although a single allocation system would help ensure equitable access to deceased organs based on clinical evidence, unless donation rates in all regions are equally high, a single allocation system will only increase waiting times in regions with high donation rates and decrease waiting times in regions with low donation rates. Some Panel members believe that a single provincial allocation system for deceased livers and kidneys would penalise regions that have a strong donation culture, make deceased organ donation a high priority and are high performing deceased donor regions.

All Panel members agree that there must be equitable access to organs in Ontario based on clinical evidence. As well, the majority of members agree that a single system should be used to allocate deceased donor organs across Ontario especially given that not everyone has an equal chance of accessing live donors. The Panel could not reach consensus on when such a system should be put in place. Options included: i) within a certain time of the acceptance of this report by the Ministry of Health and Long-Term Care; and ii) when the deceased organ donation rates in each region achieve an equally high level of performance (equal to or beyond those in high performing regions such as London).

The Panel recommends that:

R17 Trillium Gift of Life Network and the transplantation community review the allocation and distribution of organs in Ontario and identify improvements to ensure that Ontarians have equitable access to organ transplants based on clinical evidence.

12.2 AN INTEGRATED APPROACH TO RECOVER, PROCESS AND ACCESS TISSUE

The second element of equitable access to organs and tissues is an integrated approach to recover, process and access tissue. In November 2006, Trillium submitted to the Ministry a *Strategic Plan to Improve Tissue Donation Activities in Ontario*.[45] Tissue includes corneas, skin, bone, cardiovascular tissue (heart valves and veins) and connective tissue (tendons, ligaments). One donor can provide tissue for as many as 75 recipients. Tissue recovery tends to be largely focused in the Greater Toronto Area and is performed by physicians who are interested and willing to recover tissue, by medical residents,[46] and by International Medical Graduates.

As noted in Chapter 8, Ontario has six tissue banks and as many as 15 hospital-based surgical bone banks all of which work independently of each other. Efforts are underway in Thunder Bay to implement a surgical bone and deceased donation tissue bank. According to Trillium's tissue strategic plan, Ontario's six tissue banks meet less than 8% of the provincial demand for allograft tissue, producing and distributing about 3,600 grafts annually. Except for cornea, however, Ontarians do not appear to wait for other types of tissue: hospitals and dental clinics meet demand by purchasing allografts from Canadian and American tissue banks at an estimated cost of about $19 million per year. Periodontists, oral maxiofacial surgeons and dentists are the most prevalent end users of advanced allograft tissue products. The most common implanted allograft is demineralized bone, a product currently not produced in Canada.

In response to the Tissue Strategic Plan, the Ministry provided Trillium with one-time funding of $936,700 in 2007/08 and $910,700 in 2008/09 to support tissue donor consent and screening (see Chapter 11.3, Recommendation 11). A portion of this funding has been used to establish ocular recovery teams in the Greater Toronto Area.

In the Panel's view, there is an incredible opportunity for Ontario to create a coordinated approach to recover, process and access tissue in the province, and potentially in Canada. The higher the volume of tissue, the lower the unit cost for processing. More importantly, an integrated approach would help ensure that Ontarians have equitable access to safe, high quality tissue rather than depend on a "local supply" which may or may not exist, and may or may not meet quality standards.

The Panel supports developing *one coordinated tissue recovery system* for all of Ontario. The recovery system should be managed by Trillium which would be accountable for setting quality and safety standards, coordinating activities, monitoring best practices and improving performance. The Panel agrees that physicians are not needed to harvest tissue, rather technicians can be trained to harvest multiple types of tissue. This would also support quality and safety standards and the consistent use of best practices.

[45] Trillium Gift of Life Network. 2006 (November 6). *Strategic Plan to Improve Tissue Donation Activities in Ontario*.

[46] The Professional Association of Interns and Residents (PAIRO) strongly supports clinical activities that are for educational purposes only.

Different models could be used for recovery teams (e.g., hire and train recovery technicians to be on call to recover tissue; contract out with recovery teams through a Request for Proposals process, etc.). It has been suggested that Ontario would probably need three tissue recovery teams to serve the province (London, Ottawa and the Greater Toronto Area). The need for a recovery team to cover Northern Ontario should also be explored further.

The Panel further supports developing a *coordinated, not-for-profit tissue processing and accessing system* to meet the needs of Ontarians for tissue. The system should take a provincial consortium approach with several sites operating within a single management structure (similar to the Shared Information Management System or SIMS), and coordinate and integrate the efforts of the current tissue banks in Ontario. The distribution system should be linked directly to Trillium through its TOTAL information system. Hospitals should be encouraged to purchase their tissue from the Ontario processing and distribution system on a cost-recovery basis. This system would build on the investments made by the current tissue banks and by the Ontario government, promote economic development and skilled jobs in Ontario, and enable Ontario's hospitals to purchase Ontario tissue and, thereby, reinvest taxpayer's money in the local economy. Such an integrated approach would help ensure that Ontarians have equitable access to safe, high quality tissue.

The tissue recovery, processing and accessing system should be not-for-profit and operate on a cost-recovery basis. The Ministry should consider providing funds to assist with start up operations with the expectation that these funds will be paid back to the province in due course. If the recovery and processing operations are successful, consideration should then be given to offering tissue out of province.

The Panel recommends that:

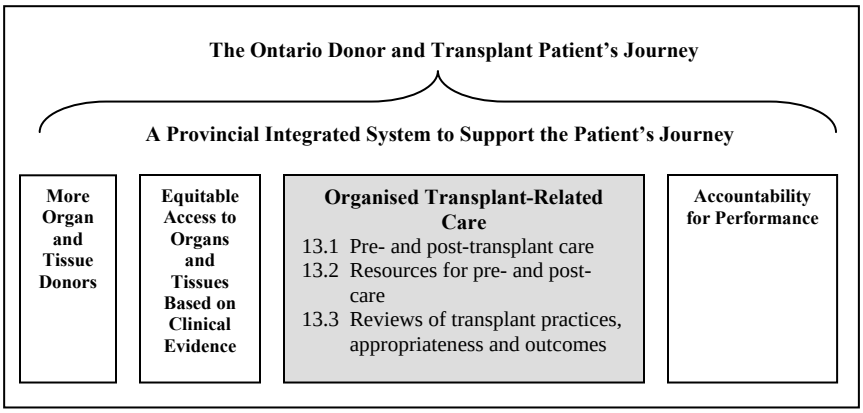
R18 The Ministry of Health and Long-Term Care support the development of *one coordinated tissue recovery system for Ontario*. The recovery system should be managed by Trillium Gift of Life which would be held accountable for setting quality and safety standards, coordinating activities, monitoring best practices and improving performance. Different models should be considered for recovery teams which should be made up of technicians trained to harvest multiple types of tissue (e.g., hire and train recovery technicians to be on call to recover tissue; contract out with recovery teams through a Request for Proposals process, other). The tissue recovery system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.

The Panel further recommends that:

R19 The Ministry of Health and Long-Term Care support the development of a *coordinated, not-for-profit tissue processing and accessing system* to meet the needs of Ontarians for tissue. The system should take a provincial consortium approach with several sites operating within a single management structure, and coordinate and integrate the efforts of the current tissue banks in Ontario. This system should build on the investments made by the current tissue banks and by the Ontario government, promote economic development and skilled jobs in Ontario, and enable Ontario's hospitals to purchase Ontario tissue and, thereby, reinvest taxpayer's money in the local economy. The tissue processing and distribution system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.

13. COMPONENT THREE: ORGANISED TRANSPLANT-RELATED CARE

Organised transplant-related care is increasingly important as more Ontarians become candidates for a transplant, go on to receive a transplant, and live into older ages with a transplant. Pre-care begins when the decision is made that a person needs a transplant and continues with life-long care after the transplant.



The Panel supports the following initiatives for organised transplant-related care:

- Pre- and post-transplant care (13.1)
- Resources for pre- and post-care (13.2)
- Reviews of transplant practices, appropriateness and outcomes (13.3)

13.1 PRE- AND POST-TRANSPLANT CARE

Members of the Panel who are organ recipients highlighted the importance of pre- and post-transplant care that includes clinical and psycho-social support, education and information. Providing this care locally, where possible, is especially important for patients who do not live near a transplant centre.

Ontario does not have standard best practice guidelines for the pre- and post-care of transplant patients. These guidelines are important since they would identify the care that the transplant centre needs to and should provide, and the care that can be provided in the local community or small hospital, and by primary care and other community-based providers. For example, the Panel noted that smaller local hospitals could conduct certain tests and forward the results to the transplant hospital. This would enable patients to stay in their local communities.

Ontario's transplantation community needs to compile and/or develop pre- and post-care best practice standards and guidelines by organ, and ensure that healthcare providers use these standards and guidelines to inform their care (e.g., transplant specialists, other specialists, physicians providing care in the community and small hospitals, primary care providers, community-based care providers, etc.). Other jurisdictions such as Atlantic Canada (Halifax) and British Columbia (Vancouver) have excellent pre- and post-care transplant programs that are provided locally. The experiences of these jurisdictions can inform the work that needs to occur in Ontario.

In addition, Ontario's transplantation community should support the use of these best practice standards and guidelines using a number of approaches that include but are not limited to:

- Targeting education programs on the care of pre- and post-transplant patients to specialty teams in local hospitals, local primary care providers and community care access centres.
- Linking the transplant specialist with the care team in the local hospital, local primary care providers and community care access centres for consultation and information. This is especially important in northern and rural areas where the Ontario Telemedicine Network should play a valuable role facilitating these links.
- Creating transplant patient and provider portals that are password-protected and enable providers and patients to obtain pre- and post care information, and enable all providers involved in the care of a patient to obtain and share information.

The Panel recommends that:

R20 Ontario's transplantation community compile and/or develop pre- and post-care best practice standards and guidelines by organ, and ensure that healthcare providers use these standards and guidelines to inform their care. The transplantation community should support the use of these standards and guidelines using a number of innovative approaches such as: i) targeting education programs; ii) linking the transplant specialists with care teams in local hospitals, with local primary care providers and community care access centres (this is especially important in northern and rural areas with the support of the Ontario Telemedicine Network); and iii) creating transplant patient and provider portals for information sharing and support.

People who are waiting for an organ can do a great deal to help themselves. The Panel supports the development of a resource manual for people waiting for an organ donation

that includes such information as what the hospital and doctor should be doing for the patient and what the patient can do while waiting for an organ (e.g., prototype letter explaining one's need for an organ; advice on approaching one's community, religious group and workplace colleagues; other information). This manual should be developed by the transplantation community, Trillium, transplant recipients, and other organisation such as the heart and stroke, kidney and liver foundations.

The Panel recommends that:

R21 Ontario's transplantation community – in collaboration with Trillium Gift of Life Network, transplant recipients, and other organisations such as the Heart and Stroke Foundation of Ontario, the Kidney Foundation of Canada and the Canadian Liver Foundation – develop a resource manual for people waiting for an organ. The manual should include information on what the hospital and doctor should be doing for the patient and what the patient can do while waiting for a transplant.

13.2 RESOURCES FOR PRE- AND POST-CARE

Patients who must be hospitalised while they wait for an organ can use significant hospital resources including non-transplant clinical services. At the time of the Panel's work, it was noted that five out of 18 cardiac critical care beds at The Hospital for Sick Children had children waiting for a heart transplant.

Hospitals fund pre- and post-transplant care through their global budgets. Through the Ontario Medical Association agreement, specialists working with adult transplant patients are compensated with specialty "repair funding."[47] If more pre- and post-transplant care is to be provided locally, local providers will have to be compensated appropriately for this work. Currently, it is difficult to get family physicians and general paediatricians to take on transplant patients largely due to the lack of reimbursement.

The Panel recommends that:

R22 The Ministry of Health and Long-Term Care and the Ontario Medical Association (OMA) address the issue of physician compensation for pre- and post-transplant care within the current OMA funding envelope.

13.3 REVIEWS OF TRANSPLANT PRACTICES, APPROPRIATENESS AND OUTCOMES

People who are waiting for an organ typically need a great deal of clinical care before they receive their transplant. This includes vital organ support such as dialysis or mechanical support, and continuous re-assessment of one's suitability for transplant (e.g., HLA testing for kidneys four times a year, other tests). Algorithms are used to determine

[47] "Repair funding" is base funding for disciplines, specialties or programs that need immediate attention.

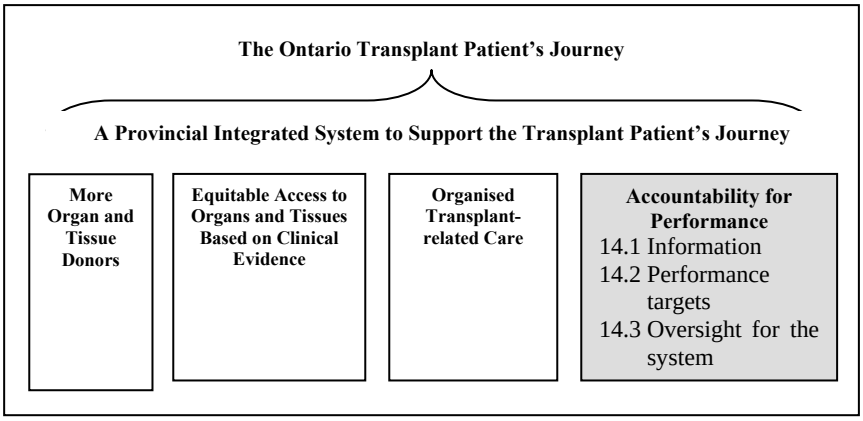
whether a patient should remain on an organ wait list and the patient's probable outcome. Although this is not an exact science and the clinical judgement of the clinician is paramount, it appears that the criteria used to determine who gets on an organ transplant wait list and who stays on the wait list varies by transplant centre and surgeon. Generally, physicians are not held accountable for who receives a transplant and the outcomes of the procedure. The Canadian Cardiac Transplant Network conducts an annual formal national review of its high status transplant cases to discuss *appropriateness issues and outcomes*, and recommend improvements. To ensure quality standards, the Panel believes this process should be used for all transplant cases in Ontario.

The Panel recommends that:

R23 Trillium Gift of Life Network and the transplantation community establish a system to monitor the use of best practice standards and guidelines for adult and paediatric organ transplantation, and the outcomes of these procedures. These stakeholders should conduct a regular provincial case review process made up of organ-specific committees and external reviewers who audit cases using agreed-upon criteria. These reviews should discuss *appropriateness issues and outcomes*, and recommend improvements.

14. COMPONENT FOUR: ACCOUNTABILITY FOR PERFORMANCE

A key cornerstone of Ontario's Wait Time Strategy has been accountability for performance. This has been supported with information that is valid and transparent, targets for performance, and clear oversight for the system of care. Everyone involved in supporting the transplant patient's journey must be held accountable for their performance.



14.1 INFORMATION SYSTEM

The *Trillium Gift of Life Act* outlines objects of the agency which include two related to information:

- To establish and manage waiting lists for the transplant of tissue and to establish and manage a system to fairly allocate tissue that is available.
- To collect, analyse and publish information relating to the donation and use of tissue.

Trillium's information system – known as TOTAL – is a central provincial donor and recipient registry that is used to facilitate organ and tissue donation. The system has over 800 registered users including transplant programs, coordinators, laboratories, technologists, and others. Hospitals provide information to Trillium on who is waiting for an organ or tissue. Trillium manages the transplant list, matches donors and recipients, and coordinates the procurement and delivery of donated organs and tissue to transplant teams. In addition to collecting the time that recipients wait for an organ, TOTAL also incorporates a clinical decision support system. TOTAL does not collect patient information after a transplant has been received; rather individual transplant centres collect this information. Trillium's website does not provide detailed information on wait times for organ or tissue transplants for Ontario or by transplant centre.

Ontario has made significant progress developing a single provincial Wait Time Information System (WTIS) that links all hospitals participating in the Wait Time Strategy. The WTIS provides near real-time information on wait times. This information is used to monitor progress made in reducing wait times and to identify areas for improvement. Wait time information is collected – from the decision to treat to treat – for cancer surgery, cardiac procedures, ophthalmic surgery, orthopaedic surgery, MRI and CT, general surgery and paediatric surgery. Specific paediatric surgical wait times and adult wait times for specialty surgeries will be publicly reported in the Fall of 2009. eHealth Ontario – an agency of the Provincial Government – oversees the WTIS and is responsible for its performance.

The Organ and Tissue Transplantation Wait Times Expert Panel was created as part of the provincial effort to improve access to and reduce wait times for a broad range of healthcare services. In keeping with transparent public reporting of wait times, the Panel supports publicly reporting organ transplant wait times on the provincial Wait Times website by hospital and type of organ (www.ontariowaittimes.com). As noted in Chapter 8, the website already reports wait times for cornea transplants. The targets for this procedure were developed by the provincial Ophthalmology Expert Panel chaired by Dr. Philip Hooper. Since all other tissues tend to be purchased immediately, it does not make sense to report publicly on the wait times for other tissues.

After reviewing Trillium's information system, it was determined that organ transplant wait times can be extracted from the TOTAL system for the purpose of public reporting on the Wait Times website. Before this can occur, however, expert clinicians need to develop a consistent standard definition of when a wait begins. It appears that clinicians are using various definitions of "wait time" for an organ. For most organs, the wait appears to begin when the decision is made for an organ transplant. For kidney, some physicians begin the wait time when a patient goes on dialysis. Other physicians do not register their patients when they begin dialysis but enter this information in the system retroactively when the decision is made to try obtaining an organ. Some patients are not even put on wait lists: only about 13% of Ontarians on dialysis appear on kidney wait lists (Chapter 7).

To align with the Wait Time Strategy and the supporting Wait Time Information System (under eHealth Ontario), expert clinicians need to develop a priority rating system for patients waiting for an organ transplant. As with all wait time information, transplant wait times will be reviewed and approved for release by the Provincial Data Certification Council. The wait times website will include links to the Trillium site for additional information.

The Panel recommends that:

R24 The Ministry of Health and Long-Term Care's Wait Time Information Program – under the direction of eHealth Ontario – work with expert transplant clinicians to develop a consistent standard definition of wait time for an organ, and a provincial priority rating scale with target time frames for organ transplants in Ontario. Using these definitions, the Ministry should extract this wait time information from Trillium Gift of Life's TOTAL information system, and publicly report organ transplant wait times on Ontario's wait time website.

14.2 PERFORMANCE TARGETS

The second element of accountability for performance is performance targets which identify what each player is expected to accomplish. Unlike performance measures, targets focus on action and improvement. To have more impact, performance targets should be included in accountability agreements between decision makers with consequences for non-performance.

A number of performance-related initiatives are being developed in organ and tissue donation and transplantation. One initiative is Accreditation Canada's standards for organ and tissue donation and transplantation.[48] Begun in 2006, an Advisory Committee is overseeing the development of standards which will be pilot tested in the spring of 2009 and finalised this year.

Accreditation Canada's ***donation standards*** are for acute care organisations with a donation or procurement team that provides organ and tissue donation services. Donation standards include:

- Investing in organ and tissue donation services;
- Engaging prepared and proactive staff;
- Assessing the suitability of donors in a consistent and sensitive manner;
- Recovering organs and tissues safely and effectively;
- Caring for living donors and families following donation;
- Maintaining accessible and efficient clinical information systems; and
- Monitoring quality and achieving positive outcomes.

[48] See http://www.accreditation.ca.

Accreditation Canada's ***transplantation standards*** are for acute care organisations that provide transplant services:

- Supporting and investing in organ and tissue transplantation services;
- Engaging prepared and proactive staff;
- Selecting donation recipients in an equitable and transparent manner;
- Providing safe and effective transplant services; and
- Monitoring quality and achieving positive outcomes.

A second initiative is Trillium's work on developing a dashboard with performance measures for organ and tissue donation. Potential measures that are being considered include timely referral rate, approach rate, effective requesting rate, consent rate, conversion rate, and organ/tissue yield.

The Panel supports the use of performance measures and explicit targets for donation and transplantation that link adequate resources for these activities to outcomes and accountabilities for performance.

With regard to Trillium, currently the agency submits an annual Business Plan to the Ministry that includes goals and budget requirements for organ and tissue donation-related activities. Trillium is accountable to the Ministry through its Board which is appointed by Order-in-Council. Trillium and Ministry staff meet regularly to discuss progress in achieving the goals outlined in the agency's Business Plan. Generally, the Business Plan includes projects and initiatives. Performance indicators and specific targets for donation and transplantation are not included in the Business Plan (e.g., number of registered organ donors, number of deceased donors, etc.)

With regard to transplant and donor hospitals, the Ministry negotiates service agreements with the 14 Local Health Integration Networks; the LHINs in turn negotiate service agreements with the hospitals. These Health Service Accountability Agreements include negotiated targets in selected areas (e.g., procedure wait times, alternate level of care rates, etc.). Currently, performance indicators and specific targets for donation and transplantation are not included in these agreements.

Targets for Trillium and transplant and donor hospitals need to be included in appropriate accountability agreements (e.g., Trillium Business Plan; Trillium-hospital agreements; Ministry-LHIN-hospital agreements). Trillium, transplant hospitals, donor hospitals and others should be measured on their performance and results. When Accreditation Canada's standards have been released, donation and transplantation standards should be linked with accreditation for both Trillium and the transplant hospitals.

Based on the Panel's review of the literature and data, and the recommendations contained in this report, a list of potential performance indicators for donation and transplantation are presented below (Table 19).

Table 19: Potential Performance Indicators for Donation and Transplantation (Note: Targets need to be developed for each indicator)	
1.	Number of registered organ donors
2.	Donation rate per million by province and region
3.	Number of living and deceased organ donors by province, region, hospital
4.	Number of donations after cardiac death by province, region, hospital
5.	Number of donations after neurological determination of death by province, region, hospital
6.	Number of deceased tissue donors by province, region, hospital
7.	Number of people on organ waiting lists by province, region, hospital
8.	Waiting time for organs by province, region, hospital
9.	Number of deaths on organ wait lists by province, region, hospital
10.	Referral rate by province, region, hospital
11.	Approach rate by province, region, hospital
12.	Effective requesting rate by province, region, hospital
13.	Consent rate by province, region, hospital
14.	Conversion rate by province, region, hospital
15.	Organ/tissue yield by province, region, hospital
16.	Number of living and deceased organ transplants by province, region, hospital
17.	Number of transplanted tissues by province, region, hospital
18.	Hospitals with Level 3 critical care units: • Have a designated donation champion (Rec. 5) • Have a well-functioning Organ and Tissue Donation Committee (Rec. 6) • Rate of notification of Trillium after discussion and decision to withdraw life sustaining therapies and before the withdrawal of these therapies (Rec. 7) • Use of standard policies for Donation After Neurological Death and Donation After Cardiocirculatory Death to guide clinical practice (Rec. 8)
19.	Initiatives that indicate LHIN Critical Care Leads and Emergency Room Leads are promoting and supporting organ and tissue donation in critical care units and emergency departments in their LHINs as part of end-of-life care (Rec. 9)
20.	Appropriate alerts provided to Trillium by the Critical Care Information System, CritiCall and the Emergency Neurosurgery Image Transfer System to enable the agency to evaluate the potential for donation (Rec. 14).
21.	Number and rate of neurosurgical calls about donation opportunities after viewing the Emergency Neurosurgery Image Transfer System (Rec 14)
22.	Use of pre- and post-care best practice standards and guidelines by healthcare providers to inform care (Rec 20)
23.	Organ and tissue donation as part of end-of-life care integrated into provincial strategies by the Critical Care Secretariat, Neurosurgery Expert Panel, and Emergency Room/Alternate Level of Care Expert Panel. (Rec. 9)

Performance objectives for Trillium as set out in the *Trillium Gift of Life Network Act* are presented in Table 20. These objectives should be used to set performance indicators and targets for Trillium to be included in its annual Business Plan.

Table 20: Performance Objectives for Trillium Gift of Life Network as Set Out in the *Trillium Gift of Life Network Act*, 8.8 (Note: Performance indicators and targets need to be developed for each objective)	
1.	To plan, promote, co-ordinate and support activities relating to the donation of tissue for transplant and activities relating to education or research in connection with the donation of tissue.
2.	To co-ordinate and support the work of designated facilities in connection with the donation and transplant of tissue.
3.	To manage the procurement, distribution and delivery of tissue.
4.	To establish and manage waiting lists for the transplant of tissue and to establish and manage a system to fairly allocate tissue that is available.
5.	To make reasonable efforts to ensure that patients and their substitutes have appropriate information and opportunities to consider whether to consent to the donation of tissue and to facilitate the provision of that information.
6.	To provide education to the public and to the health care community about matters relating to the donation and use of tissue and to facilitate the provision of such education by others.
7.	To collect, analyse and publish information relating to the donation and use of tissue.
8.	To advise the Minister on matters relating to the donation of tissue.
9.	To do such other things as the Minister may direct. 2000, c. 39, s. 5.

The Panel recommends that

R25 The Ministry of Health and Long-Term Care, Trillium Gift of Life Network, and the donation and transplantation communities identify performance indicators and set targets for donation and transplantation that are *linked to outcomes and accountabilities for performance*. These targets should be outlined in appropriate accountability agreements between the Ministry and Trillium, and between the 14 Local Health Integration Networks and transplant and donor hospitals (e.g., Trillium Business Plan; Hospital Service Accountability Agreements, etc.).

14.3 OVERSIGHT FOR THE SYSTEM

The final element to achieve accountability for performance and, ultimately, to create an integrated system to support the donor and transplant patient's journey is oversight for the system. It can be argued that system oversight is the most critical requirement for an effective and well-functioning provincial donation and transplant service. It became very clear over the course of this review that no one organisation is accountable for Ontario's provincial donation and transplantation system. Indeed, at times it was difficult to decide to whom some of the Panel's recommendations should be directed.

Trillium Gift of Life was created from a recommendation by the Advisory Board on Organ and Tissue Donation.[49] The Board recommended that Trillium become Ontario's

[49] *A Plan for Change and Action. Report of Premier Harris' Advisory Board on Organ and Tissue Donation* (Chair, Don Cherry), May 2000.

"organ procurement organisation" to manage organ and tissue donation efforts in close co-operation with – but separately from – the transplant centres. The Ontario Government created Trillium in December 2000 as Ontario's central organ and tissue donation agency. Trillium has gone on record as saying that it should continue as a separate body to manage donation and that a single organization should not be responsible for donation and transplantation.[50] The agency would like to maintain a clear separation between activities focused on donation and the care of potential donor patients, and activities focused on the care of potential recipients. Despite generous investments of taxpayers dollars, as documented in this report, and much effort, the agency's one performance target – doubling the organ donation rate from 2000 to 2005 – was not realised.[51] The new donation goal set in the *2004 Ontario Budget* for an additional 425 organ transplants by the end of 2007/2008 has not been achieved. (In 2004, Trillium reported 727 total organ transplants in Ontario; by the end of 2008, an additional 125 organ transplants were performed over this base.[52])

The transplant centres have actively participated in increasing donations through living donors. For the most part, the transplant centres continue to operate quite independently of each other. Donation rates vary across the province. Higher regional donation rates may well reflect an organisation's commitment to champion donation opportunities and keep their transplant program viable. The centres use an historical system to allocate kidneys and livers which results in the perception of inequitable access to these organs. Some transplant centres perform low volumes of transplants which calls into question whether they should be providing this highly specialised and expensive service. As well, there are no transplant centres in northern Ontario which may be needed to meet local needs for organ transplantation.

Ontarians deserve a more effective system of donation and transplantation. They deserve to have timely and equitable access to an integrated system that will support them if they need a transplant. As one Panel member noted, "if there were ever a team sport, donation and transplantation is it." With multiple players with different foci and purposes, clarifying who is responsible for the system of donation and transplantation is paramount if Ontario is to improve access and reduce wait times for transplantation.

The Panel discussed options for providing oversight for the system. One option was to expand the role of the current provincial agency to include both donation and transplantation. The other option was to create a separate parallel agency responsible for transplantation in Ontario. There are other options.

[50] Correspondence from Rabbi Reuven Bulka (Chair of Trillium) and Dr. Frank Markel (President and CEO of Trillium) to Dr. Alan Hudson (Lead, Access to Services and Wait Time Strategy), May 14, 2009.
[51] *A Plan for Change and Action. Report of Premier Harris' Advisory Board on Organ and Tissue Donation* (Chair, Don Cherry), May 2000.
[52] Trillium Gift of Life Network: www.giftoflife.on.ca. Accessed June 18, 2009.

The Panel recommends that:

R26 The Ministry of Health and Long-Term Care conduct a role review of Trillium Gift of Life Network and the transplant centres with the goal of determining the best structure to provide effective oversight for the system of donation and transplantation in Ontario.

SECTION E: ACTION PLAN AND CONSOLIDATED LIST OF RECOMMENDATIONS

15. ACTION PLAN

Transplantation significantly increases people's chances of long-term survival, improves their quality of life and is cost-effective. Ontario donor and transplant patients need to be supported with a provincial integrated system that includes more organ and tissue donors, equitable access to organs and tissues based on clinical evidence, organised transplant-related care, and accountability for performance.

The Panel presents the following action plan for the Ministry's consideration.

Recommendations can be implemented in the short term (1-6 months), medium term (6-12 months) or long term (12 months and beyond). Some recommendations are ongoing in nature. A number of medium- and long-term recommendations require planning and development before they can be implemented.

COMPONENT ONE: MORE ORGAN AND TISSUE DONORS		
Recommendations	**Responsibility**	**Timing**
R1 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a strategic marketing and education plan to increase public awareness of donation and transplantation, and build a donation culture where Ontarians believe that organ and tissue donation is part of the cultural fabric of this province. The plan should include a recommended course of action, clear deliverables, timelines and resource requirements.	• Trillium Gift of Life in collaboration with the donation and transplantation communities	• Short term to develop the plan • Medium to long term to implement the plan
R2 Trillium Gift of Life Network – in consultation with donation and transplantation stakeholders – design and conduct an epidemiological study of donor characteristics that impact on supporting living and deceased donation. The study results should be used to inform efforts to increase organ and tissue donations in Ontario.	• Trillium Gift of Life in consultation with donation and transplantation stakeholders	• Medium term to develop and complete the study
R3 The Ministry of Health and Long-Term Care support the implementation of online registration to legally record one's decision to donate organs and tissue in Ontario. Traditional means of registering by mail and through the Service Ontario Health Card Offices (OHIP) should continue.	• Ministry of Health and Long-Term Care in consultation with Trillium Gift of Life	• Short term to plan and obtain approvals • Medium term to communicate and raise awareness • Medium to long term to implement
R4 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a comprehensive organisation and healthcare provider awareness and education plan to increase awareness about organ and tissue donation. The plan should identify provincial, regional and local solutions to increase education and awareness, and actively engage the participation of organisations, professional associations, health regulatory colleges, and other groups (e.g., Ontario's Critical Care Secretariat and Neurosurgery Expert Panel). Furthermore, the plan should incorporate innovative ways to promote donation awareness (e.g., develop education programs in partnership with the health regulatory colleges that would recognise the programs as continuing education credits for professional recertification). Trillium should facilitate the implementation of the plan to help raise awareness of donation and transplantation among organisations and healthcare providers, and their clients and patients.	• Trillium Gift of Life in collaboration with the donation and transplantation communities	• Short term to develop the plan • Medium to long term to implement the plan

COMPONENT ONE: MORE ORGAN AND TISSUE DONORS		
Recommendations	**Responsibility**	**Timing**
R5 Ontario hospitals with Level 3 critical care units identify a donation champion who is responsible for working with others to sustain a strong donation culture in the organisation. The champion should be a well respected physician leader who works closely with the hospital's donation coordinator, if available.	• Critical Care Secretariat/ Provincial Critical Care Lead in partnership with Trillium Gift of Life, the transplant community and LHIN Critical Care Leads • Hospitals with Level 3 critical care units	• Short term to develop roles and responsibilities of the donation champion • Short term for hospitals to designate donation champions
R6 Ontario hospitals with Level 3 critical care units be required to establish and operate an Organ and Tissue Donation Committee.	• Critical Care Secretariat/ Provincial Critical Care Lead in partnership with Trillium Gift of Life, the transplant community and LHIN Critical Care Leads • Hospitals with Level 3 critical care units	• Short term to finalise committee terms of reference • Medium term for hospitals to develop the committees and make them operational
R7 Ontario hospitals with Level 3 critical care units be required to notify Trillium Gift of Life Network *after* the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies *and before* the withdrawal of these therapies has begun.	• Critical Care Secretariat/ Provincial Critical Care Lead in partnership with Trillium Gift of Life, the transplant community and LHIN Critical Care Leads • Hospitals with Level 3 critical care units	• Short term to develop the policy and procedures for notification, and communicate • Medium term for hospitals to implement
R8 Ontario hospitals with Level 3 critical care units adopt standard policies for *Donation After Neurological Death*, and for *Donation After Cardiocirculatory Death* that are consistent with those established by the Canadian Council for Donation and Transplantation Consensus Conference and adapted by Trillium Gift of Life Network. The Critical Care Leads for each Local Health Integration Network should ensure that the hospitals within their respective LHINs adopt these policies and use them to guide their clinical practice.	• Critical Care Secretariat/ Provincial Critical Care Lead in partnership with Trillium Gift of Life, the transplant community and LHIN Critical Care Leads • Hospitals with Level 3 critical care units	• Short term to communicate the policies • Medium term for hospitals to adopt and use policies to guide practice

COMPONENT ONE: MORE ORGAN AND TISSUE DONORS		
Recommendations	**Responsibility**	**Timing**
R9 Ontario's Critical Care Secretariat, the Neurosurgery Expert Panel, and the Emergency Room/Alternate Level of Care Expert Panel integrate organ and tissue donation as part of end-of-life care in their respective strategic areas. In addition, the Local Health Integration Network (LHIN) Critical Care Leads and Emergency Room Leads should promote and support organ and tissue donation in critical care units and emergency departments, in their respective LHINs, as part of end-of-life care.	• Critical Care Secretariat/ Provincial Critical Care Lead, Neurosurgery Expert Panel and ER/ALC Expert Panel • LHIN Critical Care and ER Leads	• Medium term for Critical Care Secretariat and expert provincial panels to integrate in their strategies • Medium term and ongoing for LHIN Leads to promote
R10 The Ministry of Health and Long-Term Care continue to fund Trillium Gift of Life Network for the donor coordinator program, assess the adequacy of the current level of support, and make any necessary adjustments.	• Ministry of Health and Long-Term Care • Trillium Gift of Life	• Short term for Ministry to continue funding • Medium term for Ministry and Trillium to assess support and for Trillium to develop business case for expansion, if appropriate
R11 The Ministry of Health and Long-Term Care provide ongoing base funding to Trillium Gift of Life Network to support tissue donor consent and screening.	• Ministry of Health and Long-Term Care	• Short term
R12 The Critical Care Secretariat of the Ministry of Health and Long-Term Care assess the critical care bed supply in the province to identify facilities that would benefit most from critical care resources to support organ and tissue donation. This should be one criterion used to allocate additional critical care capital and operating resources in the future.	• Critical Care Secretariat/ Provincial Critical Care Lead in consultation with the Ministry of Health and Long-Term Care	• Medium term
R13 The Ministry of Health and Long-Term Care review the payment schedule for organ and tissue donation and transplantation to ensure that hospitals are adequately compensated for the costs of supporting these activities. In addition, the Ministry should review physician compensation within the current Ontario Medical Association funding envelope.	• Ministry of Health and Long-Term Care	• Long term
R14 The Critical Care Secretariat and the Neurosurgery Expert Panel work with Trillium Gift of Life Network to ensure that the Critical Care Information System, CritiCall, and the Emergency Neurosurgery Image Transfer System be used as tools to provide appropriate alerts to Trillium to enable the agency to evaluate the potential for donation. In particular, neurosurgeons who are viewing the Emergency Neurosurgery Image Transfer System should be required to contact Trillium when potential donation opportunities arise.	• Critical Care Secretariat/ Provincial Critical Care Lead, Neurosurgery Expert Panel, Trillium Gift of Life, and Wait Time Information Office to facilitate	• Short term for Wait Time Office to facilitate discussions on how the information systems can be used to provide alerts • Medium term for all to implement alerts

COMPONENT ONE: MORE ORGAN AND TISSUE DONORS		
Recommendations	**Responsibility**	**Timing**
R15 The Ministry of Health and Long-Term Care – in partnership with Trillium Gift of Life Network and living donors – identify ways to enhance the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to support potential and actual living donors.	• Ministry of Health and Long-Term Care in partnership with Trillium Gift of Life and living donors	• Medium term to identify and recommend areas for improvement
R16 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a provincial program that recognises all deceased and living organ and tissue donors in Ontario.	• Trillium Gift of Life in collaboration with donation and transplantation communities	• Short term to develop a plan to support a provincial program • Medium term to implement a provincial approach

COMPONENT TWO: EQUITABLE ACCESS TO ORGANS AND TISSUES		
Recommendations	**Responsibility**	**Timing**
R17 Trillium Gift of Life Network and the transplantation community review the allocation and distribution of organs in Ontario and identify improvements to ensure that Ontarians have equitable access to organ transplants based on clinical evidence.	• Trillium Gift of Life Network and the transplantation community	• Short term
R18 The Ministry of Health and Long-Term Care support the development of *one coordinated tissue recovery system for Ontario*. The recovery system should be managed by Trillium Gift of Life which would be held accountable for setting quality and safety standards, coordinating activities, monitoring best practices and improving performance. Different models should be considered for recovery teams which should be made up of technicians trained to harvest multiple types of tissue (e.g., hire and train recovery technicians to be on call to recover tissue; contract out with recovery teams through a Request for Proposals process, other). The tissue recovery system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.	• Ministry of Health and Long-Term Care • Trillium Gift of Life	• Short term for Ministry to support development • Short term for Trillium to plan the details of the system and implementation steps • Medium to long term for Trillium to implement the system

COMPONENT TWO: EQUITABLE ACCESS TO ORGANS AND TISSUES		
Recommendations	**Responsibility**	**Timing**
R19 The Ministry of Health and Long-Term Care support the development of a *coordinated, not-for-profit tissue processing and accessing system* to meet the needs of Ontarians for tissue. The system should take a provincial consortium approach with several sites operating within a single management structure, and coordinate and integrate the efforts of the current tissue banks in Ontario. This system should build on the investments made by the current tissue banks and by the Ontario government, promote economic development and skilled jobs in Ontario, and enable Ontario's hospitals to purchase Ontario tissue and, thereby, reinvest taxpayer's money in the local economy. The tissue processing and distribution system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.	• Ministry of Health and Long-Term Care • Trillium Gift of Life	• Short term for Ministry to support development • Medium term for Trillium to plan the details of the system and implementation steps • Long term for the Ministry to facilitate implementation of the system

COMPONENT THREE: ORGANISED TRANSPLANT-RELATED CARE		
Recommendations	**Responsibility**	**Timing**
R20 Ontario's transplantation community compile and/or develop pre- and post-care best practice standards and guidelines by organ, and ensure that healthcare providers use these standards and guidelines to inform their care. The transplantation community should support the use of these standards and guidelines using a number of innovative approaches such as: i) targeting education programs; ii) linking the transplant specialists with care teams in local hospitals, with local primary care providers and community care access centres (this is especially important in northern and rural areas with the support of the Ontario Telemedicine Network); and iii) creating transplant patient and provider portals for information sharing and support.	• Ministry of Health and Long-Term Care • Transplantation community	• Medium term for the Ministry to identify a lead organisation/person to facilitate the process • Medium to long term for the transplant community to compile/develop standards and guidelines, and implement

COMPONENT THREE: ORGANISED TRANSPLANT-RELATED CARE		
Recommendations	**Responsibility**	**Timing**
R21 Ontario's transplantation community – in collaboration with Trillium Gift of Life Network, transplant recipients, and other organisations such as the Heart and Stroke Foundation of Ontario, the Kidney Foundation of Canada and the Canadian Liver Foundation – develop a resource manual for people waiting for an organ. The manual should include information on what the hospital and doctor should be doing for the patient and what the patient can do while waiting for a transplant.	• Ministry of Health and Long-Term Care • Transplantation community in collaboration with Trillium Gift of Life, transplant recipients and others (e.g., Heart and Stroke Foundation of Ontario, Kidney Foundation of Canada, Canadian Liver Foundation)	• Medium term for the Ministry to select a lead organisation/person to facilitate the process • Medium term for all others to develop the manual • Medium to long-term for Trillium and others to communicate the manual
R22 The Ministry of Health and Long-Term Care and the Ontario Medical Association (OMA) address the issue of physician compensation for pre- and post-transplant care within the current OMA funding envelope.	• Ministry of Health and Long-Term Care • Ontario Medical Association	• Medium to long term
R23 Trillium Gift of Life Network and the transplantation community establish a system to monitor the use of best practice standards and guidelines for adult and paediatric organ transplantation, and the outcomes of these procedures. These stakeholders should conduct a regular provincial case review process made up of organ-specific committees and external reviewers who audit cases using agreed-upon criteria. These reviews should discuss *appropriateness issues and outcomes*, and recommend improvements.	• Trillium Gift of Life and the transplantation community	• Medium term to plan the monitoring system and supporting processes • Medium to long term to implement a regular review process

COMPONENT FOUR: ACCOUNTABILITY FOR PERFORMANCE		
Recommendations	**Responsibility**	**Timing**
R24 The Ministry of Health and Long-Term Care's Wait Time Information Program – under the direction of eHealth Ontario – work with expert transplant clinicians to develop a consistent standard definition of wait time for an organ, and a provincial priority rating scale with target time frames for organ transplants in Ontario. Using these definitions, the Ministry should extract this wait time information from Trillium Gift of Life's TOTAL information system, and publicly report organ transplant wait times on Ontario's wait time website.	• Ministry's Wait Time Information Program in consultation with expert transplant clinicians and Trillium Gift of Life	• Short term for Wait Time office to convene meetings with expert clinicians • Medium term for Wait Time Office to communicate definitions, priority ratings and targets • Medium to long term for Wait Time Office and Trillium to extract information and post on website
R25 The Ministry of Health and Long-Term Care, Trillium Gift of Life Network, and the donation and transplantation community identify performance indicators and set targets for donation and transplantation that are *linked to outcomes and accountabilities for performance*. These targets should be outlined in appropriate accountability agreements between the Ministry and Trillium, and between the 14 Local Health Integration Networks and transplant and donor hospitals (e.g., Trillium Business Plan; Hospital Service Accountability Agreements, etc.).	• Ministry of Health and Long-Term Care • Local Health Integration Networks • Trillium Gift of Life • Donation and transplantation communities	• Short term for Ministry to lead process to identify performance indicators • Medium term for Ministry and LHINs to set targets • Medium to long term for Ministry and LHINs to include targets in appropriate performance agreements
R26 The Ministry of Health and Long-Term Care conduct a role review of Trillium Gift of Life Network and the transplant centres with the goal of determining the best structure to provide effective oversight for the system of donation and transplantation in Ontario.	• Ministry of Health and Long-Term Care	• Short term to initiate role review • Short to medium term to complete review

16. CONSOLIDATED LIST OF RECOMMENDATIONS

COMPONENT ONE: MORE ORGAN AND TISSUE DONORS

Public Awareness and Opportunities to Donate

The Panel recommends that:

R1 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a strategic marketing and education plan to increase public awareness of donation and transplantation, and build a donation culture where Ontarians believe that organ and tissue donation is part of the cultural fabric of this province. The plan should include a recommended course of action, clear deliverables, timelines and resource requirements.

R2 Trillium Gift of Life Network – in consultation with donation and transplantation stakeholders – design and conduct an epidemiological study of donor characteristics that impact on supporting living and deceased donation. The study results should be used to inform efforts to increase organ and tissue donations in Ontario.

R3 The Ministry of Health and Long-Term Care support the implementation of online registration to legally record one's decision to donate organs and tissue in Ontario. Traditional means of registering by mail and through the Service Ontario Health Card Offices (OHIP) should continue.

Organisation and Healthcare Provider Education and Awareness

The Panel recommends that:

R4 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a comprehensive organisation and healthcare provider awareness and education plan to increase awareness about organ and tissue donation. The plan should identify provincial, regional and local solutions to increase education and awareness, and actively engage the participation of organisations, professional associations, health regulatory colleges, and other groups (e.g., Ontario's Critical Care Secretariat and Neurosurgery Expert Panel). Furthermore, the plan should incorporate innovative ways to promote donation awareness (e.g., develop education programs in partnership with the health regulatory colleges that would recognise the programs as continuing education credits for professional recertification). Trillium should facilitate the implementation of the plan to help raise awareness of donation and transplantation among organisations and healthcare providers, and their clients and patients.

Strong Donation Culture in Hospitals Supported With Policies/Processes, Education, Resources and Information Alerts

The Panel recommends that:

R5 Ontario hospitals with Level 3 critical care units identify a donation champion who is responsible for working with others to sustain a strong donation culture in the organisation. The champion should be a well respected physician leader who works closely with the hospital's donation coordinator, if available.

R6 Ontario hospitals with Level 3 critical care units be required to establish and operate an Organ and Tissue Donation Committee.

R7 Ontario hospitals with Level 3 critical care units be required to notify Trillium Gift of Life Network *after* the healthcare team and the patient/substitute decision maker have discussed and made the decision to withdraw life sustaining therapies *and before* the withdrawal of these therapies has begun.

R8 Ontario hospitals with Level 3 critical care units adopt standard policies for *Donation After Neurological Death*, and for *Donation After Cardiocirculatory Death* that are consistent with those established by the Canadian Council for Donation and Transplantation Consensus Conference and adapted by Trillium Gift of Life Network. The Critical Care Leads for each Local Health Integration Network should ensure that the hospitals within their respective LHINs adopt these policies and use them to guide their clinical practice.

R9 Ontario's Critical Care Secretariat, the Neurosurgery Expert Panel, and the Emergency Room/Alternate Level of Care Expert Panel integrate organ and tissue donation as part of end-of-life care in their respective strategic areas. In addition, the Local Health Integration Network (LHIN) Critical Care Leads and Emergency Room Leads should promote and support organ and tissue donation in critical care units and emergency departments, in their respective LHINs, as part of end-of-life care.

R10 The Ministry of Health and Long-Term Care continue to fund Trillium Gift of Life Network for the donor coordinator program, assess the adequacy of the current level of support, and make any necessary adjustments.

R11 The Ministry of Health and Long-Term Care provide ongoing base funding to Trillium Gift of Life Network to support tissue donor consent and screening.

R12 The Critical Care Secretariat of the Ministry of Health and Long-Term Care assess the critical care bed supply in the province to identify facilities that would benefit most from critical care resources to support organ and tissue donation. This should be one criterion used to allocate additional critical care capital and operating resources in the future.

R13 The Ministry of Health and Long-Term Care review the payment schedule for organ and tissue donation and transplantation to ensure that hospitals are adequately compensated for the costs of supporting these activities. In addition, the Ministry should review physician compensation within the current Ontario Medical Association funding envelope.

R14 The Critical Care Secretariat and the Neurosurgery Expert Panel work with Trillium Gift of Life Network to ensure that the Critical Care Information System, CritiCall, and the Emergency Neurosurgery Image Transfer System be used as tools to provide appropriate alerts to Trillium to enable the agency to evaluate the potential for donation. In particular, neurosurgeons who are viewing the Emergency Neurosurgery Image Transfer System should be required to contact Trillium when potential donation opportunities arise.

Support and Recognition for Donors

The Panel recommends that:

R15 The Ministry of Health and Long-Term Care – in collaboration with Trillium Gift of Life Network and living donors – identify ways to enhance the Program for Reimbursing Expenses of Living Organ Donors (PRELOD) to support potential and actual living donors.

R16 Trillium Gift of Life Network collaborate with the donation and transplantation communities to develop a provincial program that recognises all deceased and living organ and tissue donors in Ontario.

COMPONENT TWO: EQUITABLE ACCESS TO ORGANS AND TISSUES

Equitable Access to Organs Based on Clinical Evidence

The Panel recommends that:

R17 Trillium Gift of Life Network and the transplantation community review the allocation and distribution of organs in Ontario and identify improvements to ensure that Ontarians have equitable access to organ transplantation.

An Integrated Approach to Recover, Process and Access Tissue

The Panel recommends that:

R18 The Ministry of Health and Long-Term Care support the development of *one coordinated tissue recovery system for Ontario*. The recovery system should be managed by Trillium Gift of Life which would be held accountable for setting quality and safety standards, coordinating activities, monitoring best practices and improving performance. Different models should be considered for recovery teams which should be made up of technicians trained to harvest multiple types of tissue (e.g., hire and train recovery technicians to be on call to recover tissue; contract out with recovery teams through a Request for Proposals process, other). The tissue recovery system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.

R19 The Ministry of Health and Long-Term Care support the development of a *coordinated, not-for-profit tissue processing and accessing system* to meet the needs of Ontarians for tissue. The system should take a provincial consortium approach with several sites operating within a single management structure, and coordinate and integrate the efforts of the current tissue banks in Ontario. This system should build on the investments made by the current tissue banks and by the Ontario government, promote economic development and skilled jobs in Ontario, and enable Ontario's hospitals to purchase Ontario tissue and, thereby, reinvest taxpayer's money in the local economy. The tissue processing and distribution system should be not-for-profit, operate on a cost-recovery basis and be responsible for repaying any start-up costs provided by Government.

COMPONENT THREE: ORGANISED TRANSPLANT-RELATED CARE

Pre- and Post-Transplant Care

The Panel recommends that:

R20 Ontario's transplantation community compile and/or develop pre- and post-care best practice standards and guidelines by organ, and ensure that healthcare providers use these standards and guidelines to inform their care. The transplantation community should support the use of these standards and guidelines using a number of innovative approaches such as: i) targeting education programs; ii) linking the transplant specialists with care teams in local hospitals, with local primary care providers and community care access centres (this is especially important in northern and rural areas with the support of the Ontario Telemedicine Network); and iii) creating transplant patient and provider portals for information sharing and support.

R21 Ontario's transplantation community – in collaboration with Trillium Gift of Life Network, transplant recipients, and other organisations such as the Heart and Stroke Foundation of Ontario, the Kidney Foundation of Canada and the Canadian Liver Foundation – develop a resource manual for people waiting for an organ. The manual should include information on what the hospital and doctor should be doing for the patient and what the patient can do while waiting for a transplant.

Resources for Pre- and Post-Care

The Panel recommends that:

R22 The Ministry of Health and Long-Term Care and the Ontario Medical Association (OMA) address the issue of physician compensation for pre- and post-transplant care within the current OMA funding envelope.

Reviews of Transplant Practices, Appropriateness and Outcomes

The Panel recommends that:

R23 Trillium Gift of Life Network and the transplantation community establish a system to monitor the use of best practice standards and guidelines for adult and paediatric organ transplantation, and the outcomes of these procedures. These stakeholders should conduct a regular provincial case review process made up of organ-specific committees and external reviewers who audit cases using agreed-upon criteria. These reviews should discuss *appropriateness issues and outcomes*, and recommend improvements.

COMPONENT FOUR: ACCOUNTABILITY FOR PERFORMANCE

Information System

The Panel recommends that:

R24 The Ministry of Health and Long-Term Care's Wait Time Information Program – under the direction of eHealth Ontario – work with expert transplant clinicians to develop a consistent standard definition of wait time for an organ, and a provincial priority rating scale with target time frames for organ transplants in Ontario. Using these definitions, the Ministry should extract this wait time information from Trillium Gift of Life's TOTAL information system, and publicly report organ transplant wait times on Ontario's wait time website.

Performance Targets

The Panel recommends that

R25 The Ministry of Health and Long-Term Care, Trillium Gift of Life Network, and the donation and transplantation communities identify performance indicators and set targets for donation and transplantation that are *linked to outcomes and accountabilities for performance.* These targets should be outlined in appropriate accountability agreements between the Ministry and Trillium, and between the 14 Local Health Integration Networks and transplant and donor hospitals (e.g., Trillium Business Plan; Hospital Service Accountability Agreements, etc.).

Oversight for the System

The Panel recommends that:

R26 The Ministry of Health and Long-Term Care conduct a role review of Trillium Gift of Life Network and the transplant centres with the goal of determining the best structure to provide effective oversight for the system of donation and transplantation in Ontario.

APPENDICES

APPENDIX 1: MEMBERS OF THE EXPERT PANEL

Name	Affiliation
Gary Levy, MD Chair	Director, Multi-Organ Transplant Program; Director, University of Toronto Transplantation Institute; CIHR/Novartis Chair in Transplantation, University Health Network (Toronto General Hospital) (Toronto Central LHIN)
Don Cousens	Transplant Recipient; Former Member of Provincial Parliament and Mayor of Markham (Central LHIN)
Rhonda Crocker Ellacott	Vice President, Emergency, Critical Care, Trauma and Surgery; Chief Nursing Officer, Thunder Bay Regional Health Science Centre (North West LHIN)
Anne Dipchand, MD	Associate Director, The Hospital for Sick Children Transplant Centre (Toronto Central LHIN)
Brenda Flaherty, RN, MPA	CIO Executive VP Clinical Operations, Hamilton Health Sciences Corporation (Hamilton Niagara, Haldimand, Brant LHIN)
Brian Flood	Transplant Recipient; Partner Torys
Allan Gross, MD	Orthopaedic Surgeon, Mount Sinai Hospital; Tissue Bank and Comprehensive Orthopaedic Transplant Program (Toronto Central LHIN)
Alan Hudson, MB	Lead, Access to Services and Wait Times for Ontario
Paul Huras	CEO, South East Local Health Integration Network (SE LHIN)
Bernard Lawless, MD	Provincial Lead, Critical Care and Trauma, Ministry of Health and Long-Term Care
Frank Markel, PhD	President and CEO, Trillium Gift of Life Network
Barry McLellan, MD	President and CEO, Sunnybrook Health Sciences Centre (Toronto Central LHIN)
Joe Pagliarello, MD	Intensivist, Department of Critical Care and Trauma, The Ottawa Hospital (Champlain LHIN)
Tess Palatino	Senior Program Consultant, Organ and Tissue Donation and Transplantation, Acute Services and Chronic Disease Unit, Provincial Programs Branch, Ministry of Health and Long-Term Care

Name	Affiliation
Sharon Pfaff	Deputy Chief Information Officer, Cancer Care Ontario
Michael Schull, MD	Provincial Lead for ER; Emergency Physician, Sunnybrook Health Sciences Centre (Toronto Central LHIN)
Michael Sharpe, MD	Intensive Care Specialist, London Health Sciences Centre (South West LHIN)
Roger Strasser, MD	Dean, Northern Ontario School of Medicine
Charles Tator, MD	Professor of Neurosurgery, University of Toronto; Former Campeau Family/Dr. C.H. Tator Chair in Brain and Spinal Cord Research, University of Toronto
David Russell, MD	Transplant Nephrologist, St. Joseph's Healthcare, Hamilton
William Wall, MD	Transplant surgeon, London Health Sciences Centre (South West LHIN)
Jeffrey Zaltzman, MD	Director, Renal Transplant, St. Michael's Hospital

Support for the Panel was provided by Joann Trypuc, PhD, Consultant to Ontario's Wait Time Strategy.

APPENDIX 2: TERMS OF REFERENCE OF THE ORGAN AND TISSUE TRANSPLANTATION WAIT TIMES EXPERT PANEL

Background

In November 2004, the Ontario Government launched the Wait Time Strategy to improve access to healthcare services in the public system by reducing the time that adult Ontarians wait for services – from the decision to treat to treat – in five areas by December 2006.53 By March 2008, the Strategy was expanded to include wait times for all paediatric, ophthalmic, orthopaedic and general surgeries; by the Spring of 2009, the Strategy will include wait times for all specialty surgeries and emergency department visits.

As part of the ongoing process to improve access to and reduce wait times for a broad range of healthcare services, the Ministry of Health and Long-Term Care is creating the Organ and Tissue Transplantation Wait Times Expert Panel. The Panel will recommend a plan to provide Ontarians with access to timely, appropriate and safe organ and tissue transplants.

With regard to organ transplants, the Trillium Gift of Life Network reported a 43% increase in the number of organ donors from 1998 to 2007 (372 to 531 organ donors).54 These organ donors included living donors (increase from 156 to 264 donors), out-of-province donors (increase from 64 to 67 donors) and donations from deceased persons (increase from 152 to 200 donors).55 From 1998 to 2007, the number of organ transplants in Ontario increased 39% from 667 to 926 transplants, while the organ waiting list increased 19% from 1,408 to 1,676 organs.56 From January 1 to November 3, 2008, there were 678 organ transplants; on November 3, Ontarians were waiting for 1,735 organ transplants.57

Ontarians usually wait unacceptably long periods of time for an organ (Table 1). On December 15, 2008, adult Ontarians had already been waiting – on average – a minimum of three years for a kidney and almost two years for a liver. Children waiting for a kidney or liver waited on average almost a year for these organs. The longer someone waits, the higher the risk of morbidity and mortality. In fact, every three days someone on the organ transplant waiting list dies.[58]

[53] The areas were cancer surgery, cardiac revascularization procedures, cataract surgery, hip and knee total joint replacements, and MRI and CT scans.
[54] Trillium Gift of Life Network, http://www.giftoflife.on.ca. Accessed January 6, 2009.
[55] It appears that in 2008, there were about 170 donations from deceased persons. Email communication, G. Levy.
[56] From 1998 to 2007, the Ontario population increased 13.8% from 11,366,000 to 12,929,000 people. (Ontario Ministry of Finance, *2008 Ontario Economic Outlook and Fiscal Review*).
[57] These organ transplants include liver, heart, kidney, lung, heart-lung, pancreas, small bowel, and kidney-pancreas.
[58] Frank Markel, President and CEO, Trillium Gift of Life Network, "Record Levels of Organ and Tissue Donations Reached in Ontario" Ministry of Health and Long-Term Care, *News Release*, February 7, 2007.

A number of hospital organ transplant programs operate across Ontario. Each hospital organizes its program independently. There may be opportunities to coordinate individual hospital efforts, ensure consistent quality and safety standards and approaches, avoid costly duplication, and maximize the use of resources.

Ontario Wait Times for Organ Transplants – Average Days Waited and Number of Active Patients Waiting by Site and Organ, as of December 15, 2008

Average Days Waited and Number of Active Patients								
Site	**Liver**	**Heart**	**Lung**	**Heart-lung**	**Kidney**	**Pancreas**	**Kidney-Pancreas**	**Small Bowel**
Toronto General Hospital	664 (N=189)	332 (N=24)	169 (N=70)	231 (N=1)	1,759 (N=311)	1,584 (N=23)	1,328 (N=30)	1,333 (N=1)
St. Michael's Hospital					2,001 (N=429)			
The Hospital for Sick Children	333 (N=6)	74 (N=8)			315 (N=8)			550 (N=4)
St. Joseph's Hosp, Hamilton					1,752 (N=207)		1,841 (N=1)	
University Hospital, London Health Sciences	718 (N=117)	268 (N=9)			2,167 (N=94)		757 (N=8)	
Kingston General Hospital					1,079 (N=11)			
Ottawa Hospital (Civic Site)		200 (N=13)						
Ottawa Hospital (General Site)					1,521 (N=144)			

Source: Trillium Gift of Life Network (Jason Lian), December 15, 2008

With regard to tissue transplants, Trillium reported that not enough tissue is being donated in the province to help Ontarians who need it.[59] In 2004, there were about 1,500 tissue donors in Ontario of which 70% were ocular tissue donors. (Only 40% of these ocular donations could be used in transplants; the rest were suitable for research or education.) Trillium estimated that Ontario's surgical and dental demand for tissue allografts in 2003 was 1,329 ocular grafts, 604 skin grafts, 414 cardiac grafts, 11,433 musculoskeletal grafts (structural bone, cancellous, tendons), and 30,306 advanced products such as freeze dried bone and demineralized bone matrix for dental applications.

Ontario has six deceased donation tissue banks and 15 hospital-based surgical bone banks all of which work independently of each other. Trillium reported that the six tissue banks meet less than 8% of the provincial demand for allograft tissue, producing and distributing about 3,600 grafts annually.[60] Hospital and dental clinics meet the

[59] Trillium Gift of Life Network. *Strategic Plan to Improve Tissue Donation Activities in Ontario: Final Report*. November 6, 2006. Tissue includes corneas, cardiovascular tissue such as heart valves and veins, bone grafts and connective tissue such as tendons and ligaments, and skin grafts.

[60] Trillium Gift of Life Network. *Strategic Plan to Improve Tissue Donation Activities in Ontario: Final Report*. November 6, 2006.

remaining demand by purchasing allografts from Canadian and American tissue banks at an estimated cost of about $19 million per year. It is unclear how many people are waiting for tissue donations in Ontario and how long they are waiting.

It is expected that the demand for organs and tissue will increase due to Ontario's aging population and the increase in chronic diseases.

Mandate

The Organ and Tissue Transplantation Wait Times Expert Panel will recommend a plan to provide Ontarians with equitable access to timely, appropriate and safe organ and tissue transplants. The Panel will address the following areas:

1. A model to increase donations which includes, but is not limited to, the following:
   - Living donors and donations from deceased persons.
   - Donation after neurological or cardiac death.
   - Public and provider awareness and communications.
   - Initiatives and incentives to increase donations.

2. Volume capacity (patient throughput) including advice on the volumes that facilities should have to perform organ and tissue transplants.

3. A model of access to high quality transplant ***care*** for Ontarians including but not limited to:
   - Best practice targets and standardisation for transplantation and follow-up care.
   - Human resource requirements (e.g., roles and responsibilities) and educational requirements.
   - Information management.
   - Cost analysis, funding and pay-for-performance incentives, where appropriate.
   - Communications and public awareness.
   - The organisation of services (i.e., optimal structure) to achieve improved access, more effective and efficient practices, and higher quality care across the continuum (e.g., acute, rehabilitation, follow-up, primary care).

4. The development of an urgency rating score to prioritize patients waiting for an organ or tissue transplant including the establishment of:
   - A standard definition of "wait time" (when the waiting time begins and ends) for and organ or tissue transplant.
   - Patient priorities and wait time targets.

The Panel is advising the Minister of Health and Long-Term Care, through Dr. Hudson, Provincial Lead, Access to Care and Wait Time Strategy.

The Panel will draw from the expertise and experience of Ontario and other jurisdictions in fulfilling its role.

Deliverables

The Panel will submit its report to Dr. Hudson by April 30, 2009.

Membership

The panel will be chaired by Dr. Gary Levy, Director, Multi Organ Transplant Program; CIHR/Novartis Chair in Transplantation, University Health Network (Toronto General Hospital).

Meetings

There will be 3-4 meetings over a four month period of time.

APPENDIX 3: SUPPORTING DATA TABLES

Table 21: All Organ Transplants in Ontario (Living and Deceased) by Hospital, 1999-2008 (See Figure 7)									
Year	**Kingston General**	**London Health Sciences**	**St. Joseph's Hamilton**	**St. Michael's**	**Hosp Sick Children**	**Ottawa General**	**Ottawa Heart Institute**	**UHN Toronto General**	**Total**
1999	9	132	51	52	54	54	22	236	610
2000	6	163	57	78	59	53	15	270	701
2001	3	161	48	77	50	46	15	243	643
2002	5	168	64	70	48	54	11	267	687
2003	10	178	59	78	51	46	13	267	702
2004	10	160	69	68	43	53	8	322	733
2005	14	143	59	88	56	72	13	326	771
2006	13	141	76	110	63	71	14	399	887
2007	5	162	92	105	67	72	14	421	938
2008	11	154	83	101	50	69	12	385	865
Total	**86**	**1,562**	**658**	**827**	**541**	**590**	**137**	**3,136**	

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 22: All Organ Transplants in Ontario (Living and Deceased) by Organ, 1999-2008 (See Figure 8)											
Year	**Kidney: Deceased**	**Kidney: Living**	**Liver: Deceased**	**Liver: Living**	**Lung**	**Heart**	**Pancreas**	**Small Bowel**	**Kidney+ Pancreas**	**Heart+ Lung**	**Liver+Kidney, Liver+Heart, Liver+Bowel**
1999	183	151	135	25	41	56	0	0	16	3	0
2000	225	168	158	16	54	64	0	0	16	0	0
2001	191	159	144	34	42	58	0	0	13	2	0
2002	204	160	151	32	56	55	5	1	20	3	0
2003	199	167	165	27	54	63	4	3	19	1	0
2004	216	173	163	40	62	56	5	1	15	2	0
2005	215	202	150	45	65	59	5	1	26	3	0
2006	253	222	160	53	83	77	5	3	24	4	3
2007	303	207	164	57	99	71	8	0	23	1	5
2008	262	219	147	53	82	62	10	1	24	3	2
Total	**2251**	**1828**	**1537**	**382**	**638**	**621**	**42**	**10**	**196**	**22**	**10**

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 23: Kidney Transplants in Ontario (Deceased) by Hospital, 1999-2008 (See Figure 9)							
Year	**Kingston General**	**London Health Sciences**	**St. Joseph's Hamilton**	**St. Michael's**	**Hosp Sick Children**	**Ottawa General**	**UHN Toronto General**
1999	7	39	27	27	11	31	41
2000	5	57	29	43	14	34	43
2001	1	48	20	38	7	33	44
2002	4	48	35	29	8	38	42
2003	7	57	27	36	8	25	39
2004	10	53	32	34	4	30	53
2005	14	47	27	29	10	37	51
2006	13	51	36	55	10	31	57
2007	5	63	52	58	14	34	77
2008	11	55	41	60	7	30	58
Total	77	518	326	409	93	323	505

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 24: Kidney Transplants in Ontario (Living) by Hospital, 1999-2008 (See Figure 10)							
Year	**Kingston General**	**London Health Sciences**	**St. Joseph's Hamilton**	**St. Michael's**	**Hosp Sick Children**	**Ottawa General**	**UHN Toronto General**
1999	2	11	24	25	11	23	55
2000	1	21	28	35	13	19	51
2001	2	20	28	39	13	13	44
2002	1	20	29	41	11	16	42
2003	3	11	32	42	12	21	46
2004		15	37	34	12	23	52
2005		15	32	59	9	35	52
2006		20	40	55	10	40	57
2007		18	40	47	5	38	59
2008		16	42	41	8	39	73
Total	**9**	**167**	**332**	**418**	**104**	**267**	**531**

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 25: Liver Transplants in Ontario (Deceased) by Hospital, 1999-2008 (See Figure 11)			
Year	**London Health Sciences**	**Hosp Sick Children**	**UHN Toronto General**
1999	53	11	71
2000	61	10	87
2001	70	5	69
2002	79	8	64
2003	95	12	58
2004	73	5	85
2005	67	16	67
2006	51	12	97
2007	59	13	92
2008	59	11	77
Total	**667**	**103**	**767**

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 26: Liver Transplants in Ontario (Living) by Hospital, 1999-2008 (See Figure 12)			
Year	**London Health Sciences**	**Hosp Sick Children**	**UHN Toronto General**
1999	5	18	2
2000	4	3	9
2001	9	6	19
2002	6	5	21
2003	1	3	23
2004	3	6	31
2005	0	3	42
2006	1	4	48
2007	3	10	44
2008	4	4	45
Total	**36**	**62**	**284**

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

Table 27: Heart Transplants in Ontario by Hospital, 1999-2008 (See Figure 13)				
Year	**London Health Sciences**	**Hosp Sick Children**	**UHN Toronto General**	**Ottawa Heart Institute**
1999	18		16	22
2000	16	18	15	15
2001	12	17	14	15
2002	14	13	17	11
2003	12	13	25	13
2004	12	14	22	8
2005	11	15	20	13
2006	11	20	32	14
2007	15	18	24	14
2008	10	14	26	12
Total	**131**	**142**	**211**	**137**

Source: Trillium Gift of Life Network. Data extracted and summarized from TOTAL by Michael Dutta, April 8, 2009.

APPENDIX 4: DEFINITIONS (TIER 1 HOSPITALS AND CRITICAL CARE LEVELS)

TIER 1 HOSPITALS

Table 28: Tier 1 Hospitals and Hospitals With Trauma and Neurological Services		
	Tier 1 Hospitals	**Trauma and Neurological Services**
1.	Children's Hospital of Eastern Ontario	X
2.	Grand River Hospital	
3.	Hamilton Health Sciences Centre (3 sites)	X
4.	Hopital Regional de Sudbury Regional Hospital	X
5.	Hospital for Sick Children	X
6.	Hotel Dieu Grace Hospital	X
7.	Kingston General Hospital	X
8.	Lakeridge Health Sciences, Oshawa site	
9.	London Health Sciences Centre (3 sites)	X
10.	Niagara Health System	
11.	Ottawa Hospital (2 sites)	X
12.	Royal Victoria Hospital	
13.	St. Mary's General Hospital	
14.	St. Michael's Hospital	X
15.	Sunnybrook Health Sciences	X
16.	The Scarborough Hospital	
17.	Thunder Bay Regional Health Sciences Centre	X
18.	Trillium Health Centre, Mississauga	X
19.	University Health Network (Western and General)	X
20.	William Osler Health Centre	
21.	York Central Hospital	

CRITICAL CARE LEVELS

Level 1
Capable of providing general ward care.

Level 2 Critical Care Unit
Capable of providing service to meet the needs of patients who require more detailed observation or intervention including support for a single failed organ system, short-term non-invasive ventilation, post-operative care, patients "stepping down" from higher levels of care or "step ups" from lower levels of care. These units provide a level of care that falls between the general ward (Level 1) and a "full service" Critical care unit (Level 3). Level 2 units do not provide invasive ventilatory support.

Level 3 Critical Care Unit
Capable of providing the highest level of service to meet the needs of patients who require advanced or prolonged respiratory support, or basic respiratory support together with the support of more than one organ system. This is generally considered a "full service" Critical Care unit despite the fact some specialized services may not be available (e.g. dialysis). All Level 3 units are capable of invasive ventilatory support.