

**REPORT OF THE  
ORGAN AND TISSUE TRANSPLANTATION  
WAIT TIMES EXPERT PANEL**

**Dr. Gary Levy  
Expert Panel Chair**

**June 2009**

## CONTENTS

EXECUTIVE SUMMARY .....	1
SECTION A: INTRODUCTION.....	1
1. Background .....	1
2. The Organ and Tissue Transplantation Wait Times Expert Panel.....	2
3. Methods Used to Inform the Panel’s work .....	3
4. Overview of the Report.....	4
SECTION B: THE CONTEXT FOR THE EXPERT PANEL’S DELIBERATIONS .....	5
5. Definitions: Understanding Organ and Tissue Transplantation .....	5
5.1 Organ Transplantation Explained.....	5
5.2 Tissue Transplantation Explained .....	6
6. The Evolution of Organised Donation and Transplantation Efforts in Ontario.....	7
SECTION C: THE PROFILE OF TRANSPLANTATION IN ONTARIO .....	10
7. Organ Donors and Transplantation .....	10
7.1 Organ Donors .....	10
7.2 Organ Transplant Services and Organ Transplants .....	17
7.3 Waiting Times for Organs .....	26
8. Tissue Donors and Transplantation .....	35
8.1 Tissue Transplant Services.....	35
8.2 Tissue Donors, the Demand for Tissue and Cornea Transplant Wait Times .....	35
9. Funding to Support Transplantation .....	37
SECTION D: THE EXPERT PANEL’S DELIBERATIONS AND RECOMMENDATIONS .....	40
10. A Provincial Integrated System to Support the Donor and Transplant Patients’ Journey.....	40
11. Component One: More Organ and Tissue Donors .....	42
11.1 Public Awareness and Opportunities to Donate .....	43
11.2 Organisation and Healthcare Provider Education and Awareness .....	46
11.3 Strong Donation Culture in Hospitals Supported With Policies/Processes, Resources and Information Alerts .....	48
11.4 Support and Recognition for Donors.....	56
12. Component Two: Equitable Access to Organs and Tissues Based on Clinical Evidence.....	57
12.1 Equitable Access to Organs Based on Clinical Evidence.....	58
12.2 An Integrated Approach to Recover, Process and Access Tissue .....	61
13. Component Three: Organised Transplant-Related Care .....	63
13.1 Pre- and Post-Transplant Care.....	63
13.2 Resources for Pre- and Post-Care.....	65
13.3 Reviews of Transplant Practices, Appropriateness and Outcomes .....	65
14. Component Four: Accountability for Performance.....	66
14.1 Information System .....	66
14.2 Performance Targets.....	68
14.3 Oversight for the System.....	71
SECTION E: ACTION PLAN AND CONSOLIDATED LIST OF RECOMMENDATIONS.....	74
15. Action Plan .....	74
16. Consolidated List of Recommendations.....	82

<b>APPENDICES.....</b>	<b>88</b>
<b>Appendix 1: Members of the Expert Panel .....</b>	<b>88</b>
<b>Appendix 2: Terms of Reference of the Organ and Tissue Transplantation Wait Times Expert Panel .....</b>	<b>90</b>
<b>Appendix 3: Supporting Data Tables.....</b>	<b>94</b>
<b>Appendix 4: Definitions (Tier 1 Hospitals and Critical Care Levels).....</b>	<b>99</b>

## 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	
<i>Organs</i>	<i>Tissues</i>
<ul style="list-style-type: none"> <li>• Heart</li> <li>• Kidney</li> <li>• Liver</li> <li>• Lung</li> <li>• Pancreas</li> <li>• Small Intestine</li> </ul>	<ul style="list-style-type: none"> <li>• Bone</li> <li>• Cardiovascular (heart valves, veins)</li> <li>• Connective (tendons, ligaments)</li> <li>• Cornea</li> <li>• Skin</li> </ul>

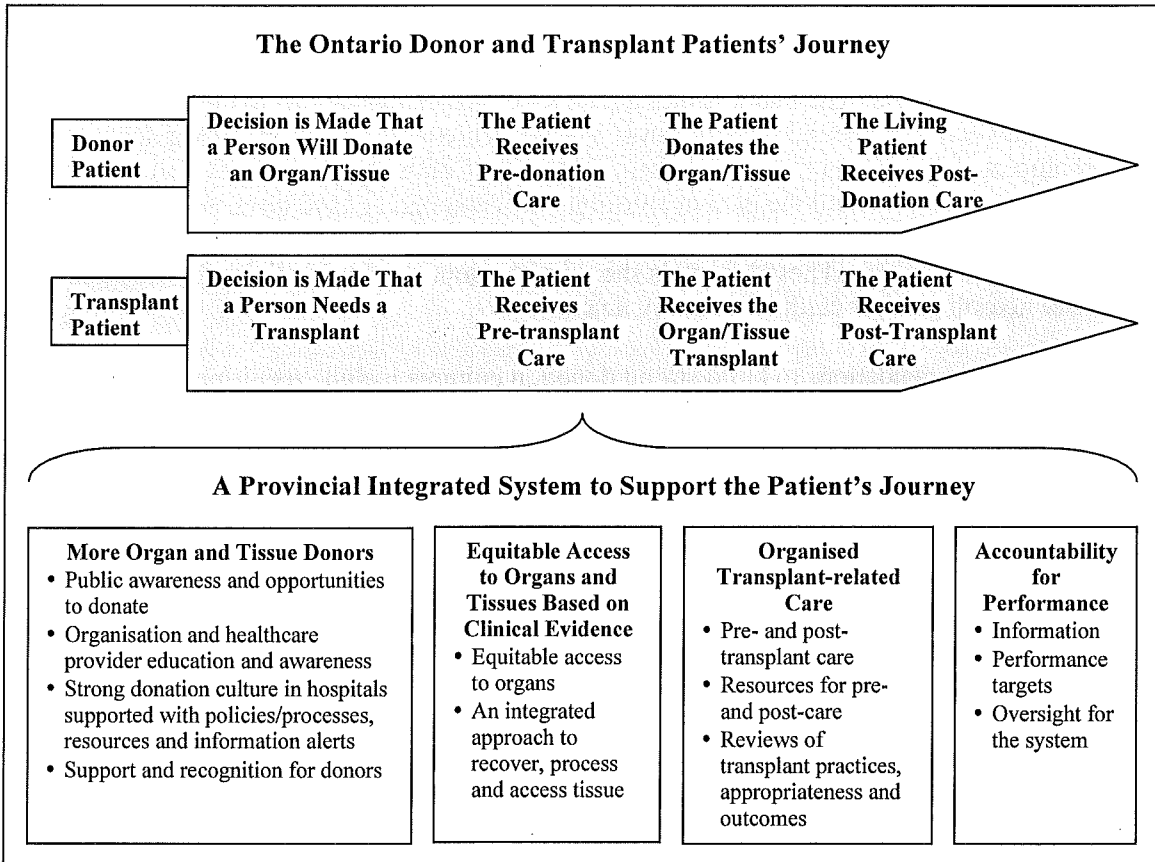
There is a shortage of organ and tissue donations in Ontario despite fairly significant investments of time and energy in the donation and transplantation systems. These include but are not limited to Trillium Gift of Life Network – an Ontario Government agency focused on organ and tissue donation – 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.