

# ORGANIZATIONAL FRAMEWORK FOR ORGAN DONATION AND TISSUE DONATION SERVICES

JANUARY 2015



Association des conseils  
des médecins, dentistes  
et pharmaciens du Québec



Blood Products  
Stem Cells  
Human Tissues



TRANSPLANT  
QUÉBEC

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# FOREWORD

## After death, a single donor can

- Save as many as **8** lives by donating organs
- Give **20**-odd people a better quality of life by donating tissues

The organ and tissue donation processes require a best-efforts approach. By stepping up these efforts and improving and streamlining the way services are organized, we can save more lives and help more people get off dialysis and recover their full potential. We can also achieve significant savings for the health-care system and society as a whole with every successful organ transplant and tissue graft.

Led by AQESSS and Transplant Québec, our four organizations joined forces to produce the Standardized Organ Donation Procedure and Standardized Tissue Donation Procedure in 2012, one year after new provisions in the Act Respecting Health Services and Social Services (ARHSSS) came into effect. With an amendment to section 204.1, the Act reaffirmed the need for every establishment to have such procedures in place.

Over time, it became clear that developing an organizational framework for organ donation and tissue donation services for establishments and councils of physicians, dentists, and pharmacists was not only a good idea, but essential. The Ministère de la Santé et des Services sociaux [ministry of health and social services, MSSS] joined our working group.

This framework is also a concrete response to the MSSS's 2004 report, *Les dons et greffes d'organes et de tissus au Québec – Plan d'action* [organ and tissue donations and transplants in Quebec: action plan]. Its purpose is to provide a critical vision of organ donation and tissue donation, each of which has its own special requirements. The framework indicates how services can be more efficiently organized both in cases of deceased donors and potential donors facing imminent death, as set out in the ARHSSS.

The end goal of these efforts is to increase the number of transplants and grafts and, as a result, save lives, reduce waiting times, and help patients regain their health, while also generating savings for the health-care system.

*Association des conseils des médecins, dentistes et pharmaciens du Québec*

*Association québécoise d'établissements de santé et de services sociaux*

*Héma-Québec*

*Transplant Québec*

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# SUMMARY

The organizational framework for organ donation and tissue donation services is a reference document intended for all health and social services establishments, in every region of Quebec, operating a hospital with a mission to offer diagnostic services as well as general medical and specialized care. Its aim is to facilitate their operations by providing a structured approach aimed at developing more effective and better performing organ donation and tissue donation services in order to better meet the needs of patients waiting for an organ or tissue transplant.

The framework is intended primarily for establishment directors, managers, and members of the Council of Physicians, Dentists, and Pharmacists (CPDP). It presents the winning conditions for establishing the proper process and implementing the means to support clinical teams in their organ donation and tissue donation activities. It is a reference document intended for all players and particularly for physicians, nurses, and respiratory therapists.

First it is essential to state that there are particularities specific to organ donation, and the same is true for tissue donation. Consequently, adapted and specific organizational arrangements must support the implementation of the proper practices. Indeed, only 1.4% of patients who die in hospital are potential organ donors, which would have represented a maximum of 344 donors in 2009, if all the conditions were met in every instance. By contrast, some 50% of people who die are potential tissue donors, which would amount, in theory, to more than 30,000 donors per year. This major discrepancy in terms of volume as well as other particularities highlights the need for separate approaches to organ donation and tissue donation, in spite of the fact that a number of considerations are similar.

The framework targets several objectives that will help to improve outcomes and performance and lead to better identification and referrals of organ donors and tissue donors. The consolidation of the establishment culture of organ donation and tissue donation also aims to achieve a more effective organization of services in compliance with legal obligations and responsibilities to the population served. The roles and responsibilities of each player are therefore presented, including those of the establishment, Transplant Québec for organ donation, and Héma-Québec for tissue donation.

In order to guide the players who work together to structure services more effectively, the framework also presents the values associated with the achievement of organ and tissue donation and transplantation. Thus, the system's ultimate objectives are to save lives (e.g., of patients waiting for a heart, liver or lung), improve quality of life (e.g., of patients waiting for a kidney, cornea or other tissue), support grieving families, and promote the expression of social solidarity. Players are guided by the core values of free and informed consent, free and universal care, equity and anonymity.

A great deal of background information is presented on the current situation regarding organ donation and tissue donation, including information on donation, patients on the waiting list, transplant recipients, and financial considerations.

In the area of organ donation, while the year 2013 demonstrated that it is possible, through a collective effort, to surpass the figure of 20 donors per million inhabitants (dpmi) and, consequently, to achieve a significant increase in the number of transplant recipients, together with a corresponding decrease in the length of the waiting list, these gains cannot be taken for granted. In fact, the results have remained stable over the last 10 years (and below the results observed in 2013). Québec can obviously do better.

The data on tissue donation, meanwhile, indicate that significant progress has been achieved, particularly in terms of the number of cornea transplants. This has a significant impact, in that it reduces the number of patients on waiting lists. The need for heart, skin, and bone tissue, as well as tendons, is so great, however, that constant vigilance is required from all stakeholders.

The framework establishes links to legislation, regulations, and normative aspects that lend structure to organ donation and tissue donation procedures, clearly setting out the obligations of establishments and, more specifically, those of directors of professional services (DPSs).

In order to direct the actions of establishments, five guiding principles are set out. **By emphasizing collaboration and coordination, these principles highlight the necessity of recognizing the shared responsibility and interdependence of establishments and organizations in order to ensure that organ donations and tissue donations are carried out.** Based on the roles of each establishment and the nature of their activities, the framework also underscores the importance of ensuring the accessibility and availability of services and resources, sharing knowledge, and supporting research (with help from Transplant Québec and Héma-Québec), with the objective of implementing best practices.

At the heart of this organizational framework, specific procedures are set out for organ donation (including support from Transplant Québec) and tissue donation (including support from Héma-Québec). This important section

- Explains the commitment, roles and responsibilities of the management team
- Reiterates the respective procedures for organ donation and tissue donation
- Emphasizes the crucial nature of forming clinical teams
- Specifies the roles and responsibilities of the organ and tissue donation committee, as well as its composition

In regard to organ donation, the importance of each player in the success of the donation and transplantation chain is reiterated, specifying (depending on whether the establishment is an identification, procurement or transplantation centre) the resources that the establishment must mobilize and the actions it must perform at each stage in the chain. The framework then explains the roles and contributions of each department concerned: emergency services, intensive care (including the heart and neonatology units), diagnostic services, medical services, pharmacy, and operating room. Also highlighted is the necessity of ensuring timely and effective interestablishment transfers each time they are required, and consultation of the clinical ethics committee where appropriate. The section concludes with a presentation by Transplant Québec explaining its mission, roles, and programs: training and support in the development of organ donation; coordination of the donation process; the respective roles of the liaison and resource nurses and the medical management team; and support for the accreditation of establishments. In addition, complete details are provided on the documentation available to health professionals and establishments: [Transplant Québec website](#); standardized organ donation procedure; Organ and Tissue Donor binder; donation process checklist; guides, policies, protocols, procedures, and forms. Information on support for communications activities in establishments is also provided, together with details on the financial support available for donor identification and organ procurement.



In regard to tissue donation, the framework explains the nature of the collaboration requested from clinical services, medical biology services (laboratories, pathology), admissions, medical records, and operating rooms in establishments, specifying their roles and expected contributions, and listing the steps to follow, as well as answers to frequently asked questions. The section concludes with a presentation by Héma-Québec explaining its mission and commitment, its roles and responsibilities with respect to tissue donation, and the implementation of best practices. The coordination program for tissue donation in hospitals is presented, together with the awareness plan framing the promotional, training and recognition activities, based on the classification of establishments (targeted centres, Category 1, or Category 2 centres) established in accordance with the volume of potential donors and the strategies deployed in support of this plan. Finally, documentation is suggested to health professionals and establishments (Héma-Québec website, standardized tissue donation procedure, quick reference card, guide, and posters).

To round out the organizational framework, conditions of success are identified:

- The development of a true culture of organ and tissue donation in each establishment, reflected in a formal commitment by the board of directors and senior directors of the CPDP, and expressed in strong leadership by the entire management team, medical teams and managers
- Proper training of physicians and clinical staff on hiring, and the development and maintenance of competencies with the objective of consolidating best practices
- The recognition of interdependencies between identification, procurement, and transplantation establishments, and the establishment of effective coordination mechanisms
- The organization of communications activities for all staff at the establishment and the public
- Active collaboration with Transplant Québec and Héma-Québec
- Pooling of expertise and support for research

The commitment of establishments, directors, managers, physicians, clinical teams, CPDPs, and organ and tissue donation committees will make it possible to improve organ donation and tissue donation outcomes. In doing so, each will play a direct part in ensuring that patients on the waiting list receive more timely transplants, while generating savings for the health-care system.

# AUDIENCE

This organizational framework for organ donation and tissue donation services is primarily intended for directors and managers of Quebec establishments with general or specialized care missions. It provides information to help them create optimum conditions for implementing processes and resources to support clinical teams in their organ and tissue donation activities.

The framework will also be of interest to potential stakeholders in the organ and tissue donation processes, including physicians, nurses and respiratory therapists, department heads, and medical program co-managers. Councils of physicians, dentists, and pharmacists (CPDPs) and establishment organ and tissue donation committees also play a key role, as do other health-care and social services professionals, such as pharmacists, social workers, and nutritionists, as well as spiritual care advisors.

# OBJECTIVES

This framework has a number of objectives, including better identification and referral of potential organ donors to Transplant Québec and potential tissue donors to Héma-Québec in order to increase the number of organ and tissue transplants carried out. These objectives are as follows:

- Strengthen the organ and tissue donation culture within establishments to actively contribute to the collective effort to save lives and improve the quality of life of people waiting for an organ or tissue transplant, wherever they may be
- Support establishments in organizing organ and tissue donation services according to their status (for organs, an identification, procurement or transplantation centre; for tissues, a target centre, Category 1 centre or Category 2 centre)
- Allow for the identification and referral of potential organ and tissue donors within establishments
- Help directors of professional services (DPSs) perform their duties with respect to organ and tissue donation
- Clarify and define the roles and responsibilities of establishments, of Transplant Québec for organ donation and of Héma-Québec for tissue donation
- Bolster procurement and donor management in establishments that carry out these activities for organ donation

Organizational procedures and proposed mechanisms to aid in achieving these objectives must take into account the unique nature of organ donation and tissue donation so that services are optimally delivered in both cases.

# VALUES

There are a number of values underpinning organ and tissue donation and transplantation. These values guide establishments internally, in their interactions with patients and families, and in their activities in the broader community and society as a whole.

The values of the organ and tissue donation and transplant system are as follows:

- Save lives
- Improve quality of life
- Support families in mourning
- Promote social solidarity

These values seek to give due weight to all important factors in the process. Thus

- The patient's consent to the donation is voluntary.
- Family and loved ones agree freely.
- The consent to organ or tissue donation respects the wishes made explicitly known by the patient (the donor).
- The donation consent is in keeping with the donor's values, such as sharing, social solidarity, mutual assistance and generosity.
- The desire of donors' families to honor their loved ones' decision to donate organs or tissues after death is respected.
- Treatment is at all times fair.
- The donation is free.
- The donation is anonymous.

With regard to organ transplantation and tissue grafting, related considerations contribute to

- Fair allocation
- Anonymity and
- Greater efforts to increase organ and tissue donation

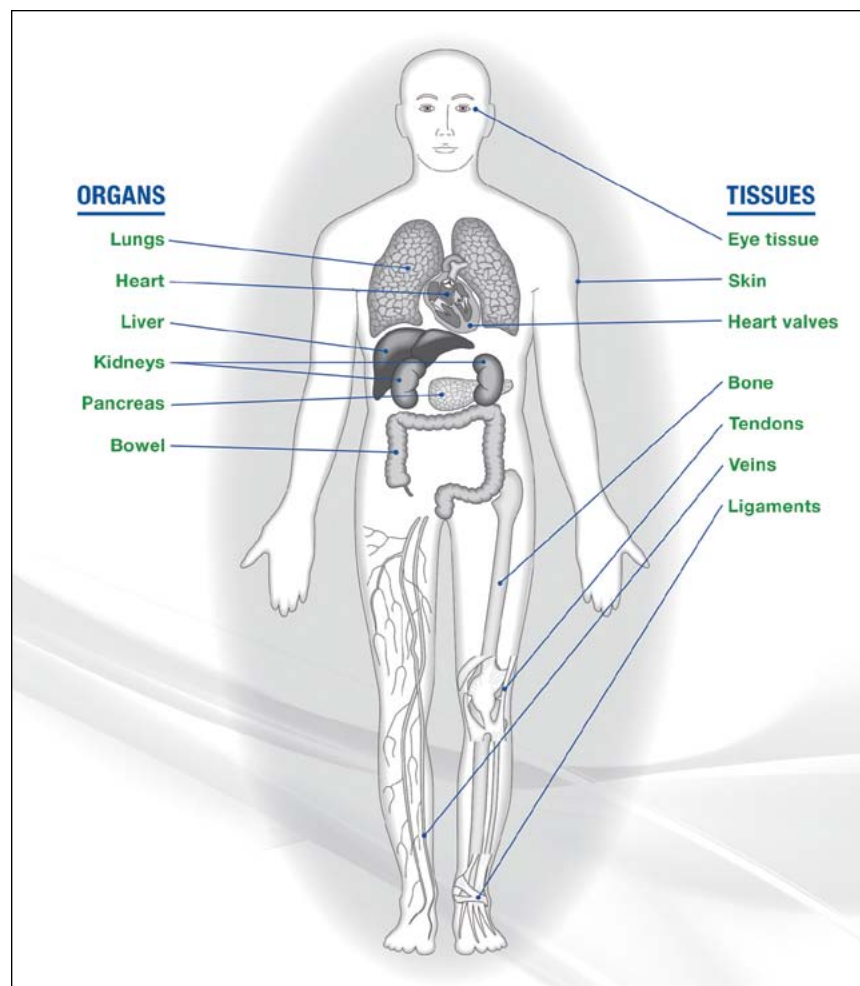
In every instance, all possible measures are taken to provide clear and inspirational guidance to the staff who make the decisions and perform the tasks involved in the donation and the grafting or transplantation process. Nothing is left to chance, so as to earn the public's trust, and especially the trust of donors, grieving families, and patients waiting for an organ or tissue transplant or graft.

# BACKGROUND AND CURRENT SITUATION

The needs for organ and tissue donation are great and establishments must actively contribute to meeting them. To be able to offer the right services, we must all be on the same page in terms of what those needs entail. There are also fundamental differences between organ donation and tissue donation. This organizational framework takes those differences into account.

After death, patients can save many lives by donating their hearts, lungs, livers (which can be divided in half and transplanted to two recipients), pancreases and bowels and can improve other people's quality of life and life expectancy by donating their kidneys. From the time they are removed, organs can be preserved for varying periods (e.g., four hours for the heart, six to eight hours for the lungs, and about 15 hours for the kidneys), depending on their resistance to cold ischemia.

Tissue preservation times also vary. Some tissues, such as eye tissue, must be transplanted within 14 days of procurement. Other tissues, such as skin, heart valves, tendons, and bone, may be preserved for up to five years using controlled freezing and cryopreservation.



For matters related to organ donation:  
**Transplant Québec**

For matters related to tissue donation:  
**Héma-Québec**

Graphic reproduced with the generous permission of the Kidney Foundation of Canada

## ORGAN DONATION

### Responding to the needs of patients awaiting organ transplants

The number of patients waiting for organ transplants has increased steadily over the past ten years, except for 2013 when, for the first time in eight years, the waiting list actually shrank and the number of donors spiked.<sup>1</sup> Yet the number of donors has remained stable over the same period, despite best efforts every day by physicians, attending teams, and Transplant Québec. Progress isn't just possible—it's necessary and it must be system-wide.

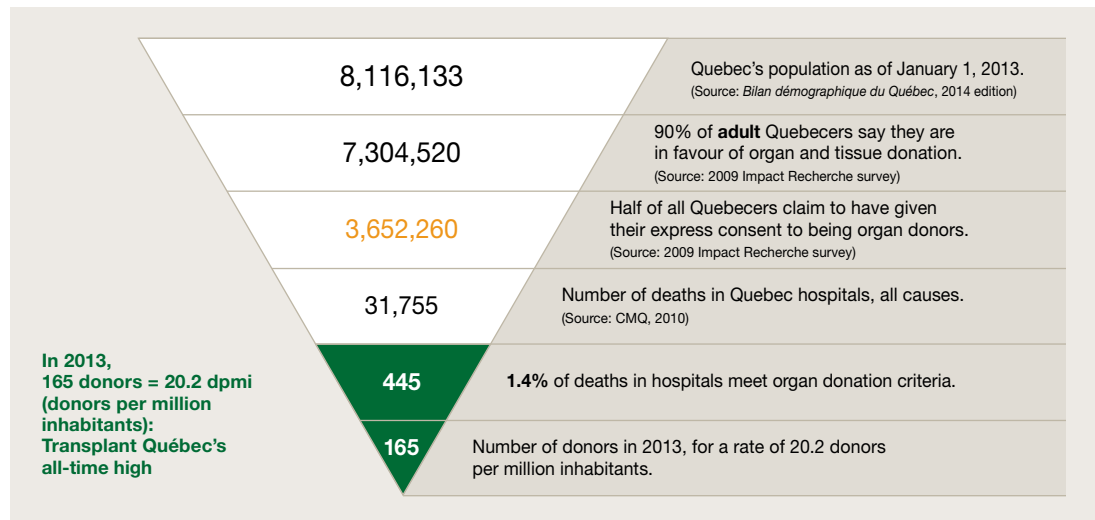
This decade-old imbalance has serious repercussions on the health of patients awaiting transplants. Their overall condition deteriorates, they withdraw socially and, all too often, they die a needlessly premature death. But establishments do have solutions within their reach. They must join forces to better address the needs of people on waiting lists all over Quebec. (See Appendix 3, under Patients on the waiting list and transplant recipients in Quebec, by region, p. 67.)

These efforts must first be deployed locally, by networking with other establishments, with the goal of increasing the number of organ donors and transplants. They will also have a positive impact on the services that many patients need. For one, more and more patients will be able to stop dialysis treatment. For another, patients waiting for an organ other than a kidney will be transplanted faster, offering the added benefit of freeing up valuable human and financial resources in clinical intervention.

ORGAN DONATION: EVERYONE'S RESPONSIBILITY.

BECAUSE EVERY CONSENT COUNTS.

### Organization of services



Source: Transplant Québec

<sup>1</sup> According to Transplant Québec data, there were 1,047 patients awaiting a transplant as of December 31, 2013, and 1,250 on the same date in 2012. Over the past decade, the number of deceased donors has fluctuated between 119 (2010) and 165 (2013). In 2013 there were 165 deceased donors, compared with 120 in 2012.

ORGAN DONORS ARE A RARE BREED: FEWER THAN 1.4% OF PEOPLE WHO DIE IN A HOSPITAL CAN DONATE.

Potential organ donors primarily come from critical care units. Identification of a potential donor sets the donation process in motion. The next step is referral. The entire organ donation process is usually completed in 24 to 48 hours.

For an organ donation to come to pass, certain conditions must be met to maintain the hemodynamic stability of the donor so the organs can be removed and transported to transplantation centres. An unidentified donor who is not recommended to Transplant Québec can have disastrous consequences for numerous recipients. It's a matter of life and death for patients awaiting the transplant of a vital organ in a transplantation centre. Considering the limited number of organ donors overall—just over 300 potential donors per year in Quebec if all conditions are met in every instance—it is paramount that all donors be identified and referred.

Transplant recipients have a good chance of survival or, for kidney transplants, of not having to return to dialysis.

- 70% to 80% of heart, liver, or lung transplant patients live for at least another five years.
- 80% of kidney transplant patients still have their graft after five years.

### ***Living donation***

While some of the considerations dealt with here could also have a positive impact on living organ donation, this organizational framework does not address that form of donation.

It is important to note, however, that the outcomes for living donation in Quebec, especially for kidneys (but also, less often, liver lobes), are well above the Canadian average and have been for a number of years. In 2013, there were 16.8 living donors per million inhabitants (549 kidneys transplanted) for Canada, but only 6.7 dpmi (53 kidneys and two liver lobes transplanted) for Quebec.

Work still needs to be done on living donations in close cooperation with existing living donation programs, and a guidebook should be developed for health-care establishments.

## CURRENT ORGAN DONATION SITUATION (AS OF DECEMBER 31, 2013)

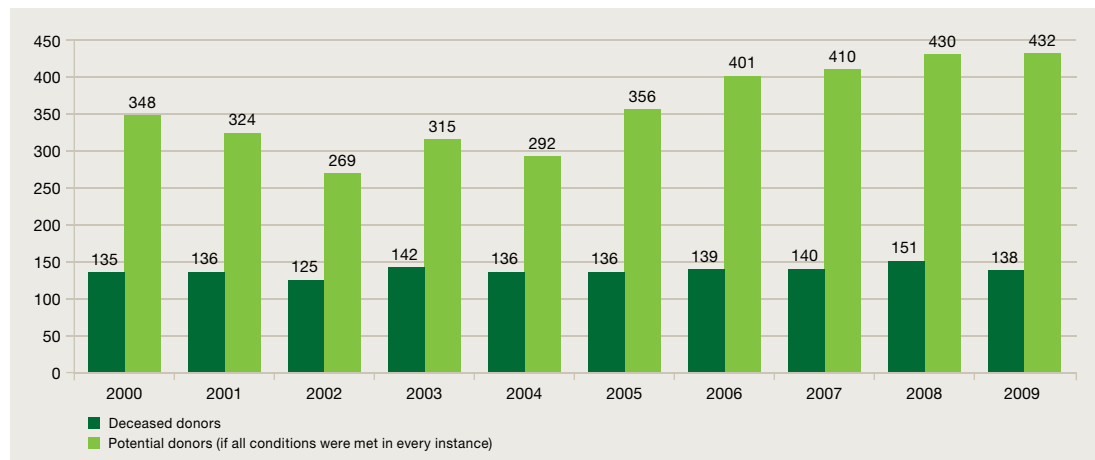
### Data on organ donation

For several years, the Collège des médecins du Québec (CMQ) has been conducting external independent audits on the overall performance of the transplant and donation system, with direct support from individual medical records departments.

The most recent study available, *Les donneurs potentiels d'organes dans les hôpitaux du Québec – Années 2000 à 2010* [Potential Organ Donors in Quebec-Based Hospitals from 2000 to 2010], reveals two findings:

- The number of potential donors is vastly different from the number of actual donors. According to the CMQ's estimate, there could have been 269 to 432 donors annually between 2000 and 2009 (depending on the year) **if all conditions had been met in every instance**.
- In 2009 there were 138 deceased donors, while the CMQ estimated there could have been as many as 344: this figure represents an adjusted success rate of 75%, including an estimated 432 potential eligible donors with a neurological determination of death (NDD) and 20 donors after cardiocirculatory death (DCD) for all of Quebec.<sup>2</sup>

#### Number of deceased and potential donors in Quebec, 2000–2009



Data source: *Organ Donors in Quebec-Based Hospitals in 2009*, CMQ

<sup>2</sup> According to the CMQ study, 344 donors would have generated a rate of 40.5 dpmi, with 1,290 organs potentially procured. The international benchmark is 75%.



**Donor identification**

According to the CMQ study, the identification rates in Quebec have varied between 66% (2000) and 88% (2003), while the target is 100%.

**Identification rates of potential donors in Quebec, 2000–2009**



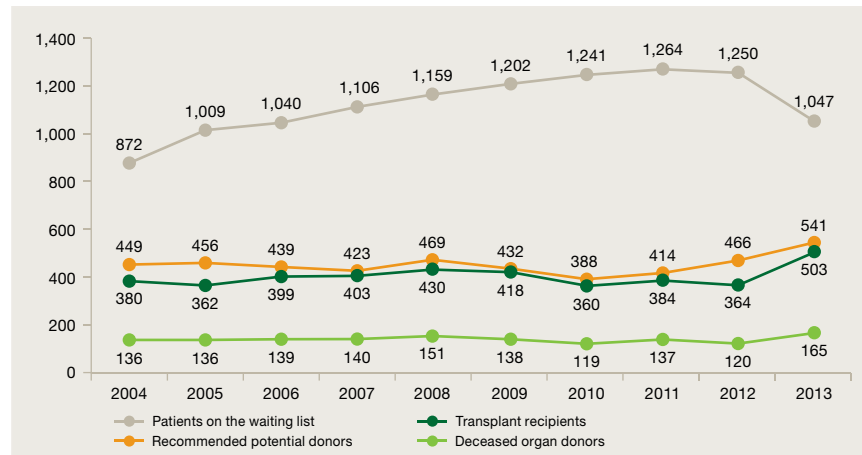
Data source: *Organ Donors in Quebec-Based Hospitals in 2009*, CMQ

**Donor referral**

The number of deceased organ donors (with a low of 119 in 2010 and a high of 165 in 2013) and patients who were able to receive a transplant (with a low of 360 in 2010 and a high of 503 in 2013) has remained stable since 2004, while the number of patients waiting for an organ went up nearly 60%, rising from 872 in 2004 to 1,250 in 2012 and dropping to 1,047 in 2013.

From 2004 to 2013, the number of referrals to Transplant Québec from health-care establishments never exceeded 541, fluctuating between 388 (2010) and 541 (2013). The 2009 CMQ study sets the theoretical potential at over 800 according to the definition of a potential donor—a person of any age with severe brain damage who is intubated and on mechanical ventilation. The benchmark target is 100%.

**Number of patients on the waiting list, recommended potential donors, transplant recipients, and deceased organ donors in Quebec, 2004–2013**

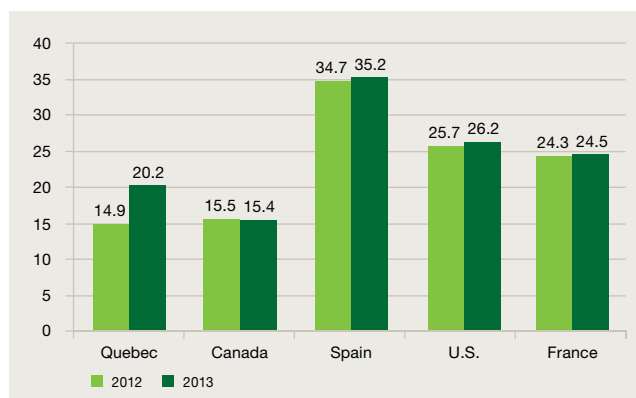


Source: Transplant Québec

With respect to the reasons for referral refusals in 2013, over one third (37%) were due to families' refusal to give their consent to organ donation, while medical reasons (medical and social history, medical conditions, unconfirmed brain death, hemodynamic instability, etc.) accounted for nearly two thirds (63%).

In 2013, the donation rate per million inhabitants exceeded 20 for the first time ever (20.2), while the low was 14.9 in 2012. The countries with the highest donation rates include France (25), the United States (26) and Spain (35).

**Rates of deceased donors per million inhabitants in Quebec, Canada, Spain, the U.S., and France, 2012 and 2013**



Source: Transplant Québec

**Family consent to donate**

According to the same CMQ study, the family consent rates for all of Quebec range from 56% (2007 and 2009) to 76% (2002), while the target is 80%.

There are three main reasons families refuse consent:

- The potential donor did not give clear written consent or the family is unaware of their loved one's wishes.
- The organ donation approach was not followed properly. A two-pronged approach (first announcing the irreversible prognosis and then proposing the option of organ donation) is preferable in these situations.
- Delays entailed by the donation, which can become taxing for a family in crisis.

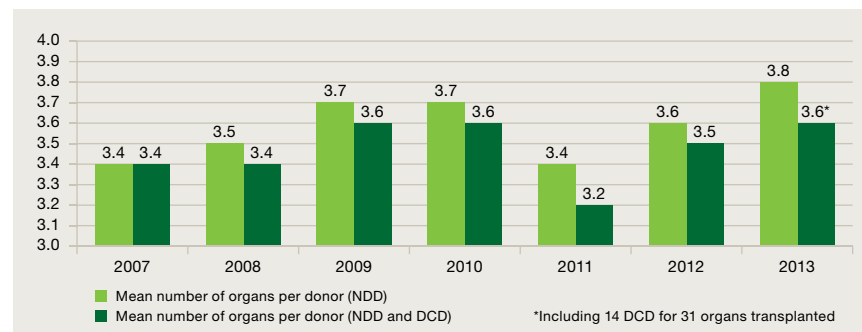
Donation after death requires careful attention, an approach tailored to potential donors and their families and a sensitivity to social and cultural factors.

Because families faced with a sudden tragedy are in shock, they must be told of the diagnosis tactfully and with compassion.

### Number of organs per donor

Between 2007 and 2013, the average number of organs transplanted per donor in Quebec ranged from 3.4 to 3.8 for NDD donors and from 3.2 to 3.6 for all donors, that is, those given an NDD diagnosis and those who donated after a DCD. The targets are 3.75 organs per donor for NDD and 2.75 per donor for DCD. These outcomes demonstrate the importance of performing an adequate assessment and optimum donor maintenance, two prerequisites to maximizing the number of organs per donor. (See Appendix 1, Distinction between NDD and DCD, p. 65.)

### Mean number of organs transplanted by donor in Quebec, 2007–2013



Source: Transplant Québec

### Characteristics of patients on the waiting list

- The likelihood someone will need an organ transplant during their lifetime greatly exceeds their odds of becoming an organ donor after death. Depending on their age, men’s odds of needing a transplant may be as much as **six** times higher than their odds of becoming an organ donor. For women, the ratio is **four** to one.<sup>3</sup>
- Nearly three quarters of the patients on the transplant waiting list need a kidney. These patients are on dialysis.
- In 2013, 38 patients died while on the waiting list. Of that number, an estimated 20% died for a reason not directly related to their need for a transplant. There were 69 such deaths in 2012 and 59 in 2011.

### Number of patients on the waiting list by organ type, 2012 and 2013

ORGAN TYPE	NUMBER OF PATIENTS WAITING	
	2012	2013
Heart	60	46
Lung	107	87
Liver	118	100
Pancreas	14	15
Kidney	923	782
Combination of organs <sup>4</sup>	28	17
<b>Total</b>	<b>1,250</b>	<b>1,047</b>

Source: Transplant Québec

<sup>3</sup> S. D. Shemie, L. Hornby, J. Chandler, P. Nickerson & J. Burkell, Lifetime probabilities of needing an organ transplant versus donating an organ after death, *American Journal of Transplantation*, 2011; 11: 2085–2092.

<sup>4</sup> Combination of organs means kidney/pancreas, heart/lung and other combinations.

## Characteristics of transplant recipients

- The average transplant recipient in 2013 was nearly 50 years old.
- From 2008 to 2013, the number of transplant recipients ranged from 360 (2010) to 503 (2013).

### Number of transplant recipients by organ type, 2012 and 2013

ORGAN TYPE	NUMBER OF TRANSPLANT RECIPIENTS	
	2012	2013
Heart	39	46
Lung	33	52
Liver	89	125
Pancreas	3	2
Kidney	187	265
Combination of organs <sup>5</sup>	13	13
<b>Total</b>	<b>364</b>	<b>503</b>

Source: Transplant Québec

## Economic issues

According to the December 2012 study by the Institut national d'excellence en santé et en services sociaux du Québec (INESSS) entitled *Analyse d'impact budgétaire d'une augmentation de la transplantation rénale au Québec* [budget impact analysis of increasing kidney transplantation in Quebec], based on the assumptions made, **an increase in the number of deceased and living donors could save the health-care system substantial amounts of money—as much as \$20 million over 10 years**. According to another study, published in November 2012 by Professor Yves Rabeau,<sup>6</sup> based on the same assumptions, **over \$50 million could be saved over a 10-year period (for 1,000 transplants in 10 years), given that nearly half of all kidney transplant recipients return to work**. The figures go even higher when you add in all transplants in Quebec.

- Kidney transplants add value, specifically in terms of the economy (dialysis), the patient, the patient's family, and society as a whole.
  - One year of dialysis for one patient costs between \$60,000 (base cost) and \$80,000, if all potential associated costs are included.
  - One kidney transplant can save \$40,000 to nearly \$55,000 per year per patient (varies by source).

<sup>5</sup> Combination of organs means kidney/pancreas, heart/lung, and other combinations.

<sup>6</sup> *The Economics of Kidney Failure*, Yves Rabeau PhD, for The Kidney Foundation of Canada – Quebec Branch, November 2012.

“Because it improves the chances of survival and the quality of life of the person with kidney failure, kidney transplantation is recognized worldwide as the most cost-effective treatment.”<sup>7</sup>

— Juan Roberto Iglesias, MD, MSc, President and CEO of the INESSS

“The use of grafts is limited by the number of available organs and the lower number of living donors, compared with the experience observed elsewhere; **this gives rise to the need to further promote organ donation.**”<sup>8</sup>

“Although the different measures designed to optimize the management of deceased-donor kidneys, to promote consent to organ removal upon death and to increase the number of living donors require funds, this investment will be quickly offset by the savings resulting from the additional transplants performed each year.”<sup>9</sup>

<sup>7</sup> *Analyse d'impact budgétaire d'une augmentation de la transplantation rénale au Québec* [Budget Impact Analysis of Increasing Kidney Transplantation in Québec], Institut national d'excellence en santé et services sociaux, December 2012.

<sup>8</sup> *Ibid.*, p. 52.

<sup>9</sup> *Ibid.*, p. 52.

## TISSUE DONATION

### CURRENT TISSUE DONATION SITUATION (AS OF MARCH 31, 2014)

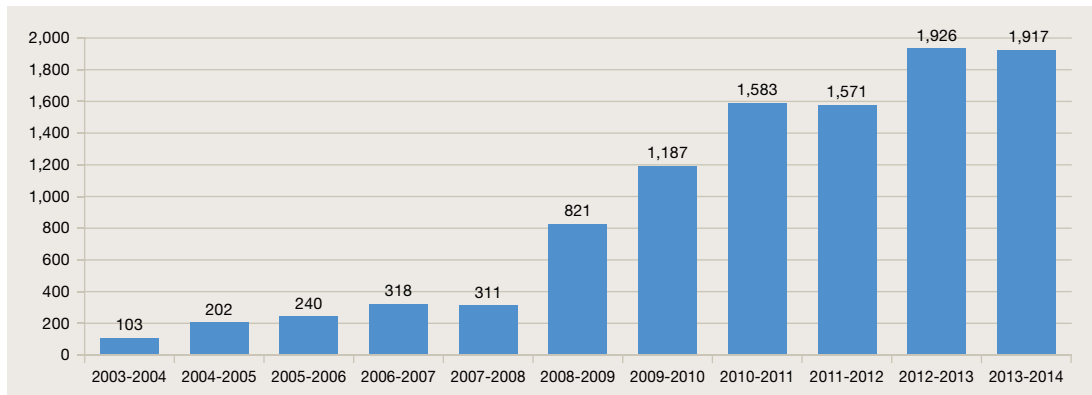
#### *High demand*

Families who have consented to tissue donation are unanimous in saying that the donation gave meaning to their loved one’s death and, in some cases, even helped them in the grieving process. **A large percentage of Quebec’s population claims to be in favour of donation and expects health-care professionals to bring the subject up when the time comes.** When families are in shock following the death of a loved one, they are unlikely to take the initiative themselves to suggest making a donation, so it is up to the health-care provider to raise the matter if donation is possible.

Patients awaiting tissue grafts are counting on donor generosity. It is the duty of health-care professionals to identify potential donors and make referrals to Héma-Québec so that this valuable donation can be carried out according to the criteria set out in the Standardized Tissue Donation Procedure.

Although potential donor referrals are increasing year over year, the demand for tissue is so high that the situation requires constant vigilance on the part of all stakeholders.

#### Number of potential donor referrals, 2003–2014

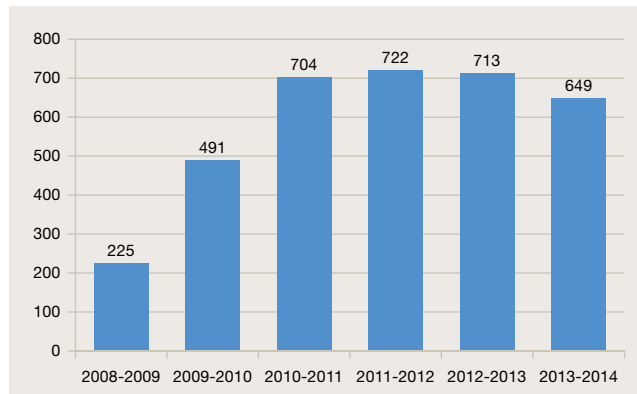


Source: Héma-Québec

## Eye tissues

Héma-Québec acts as the sole distributor of eye tissue across Quebec. In concrete terms, this means corneal surgeons identify the need and specify the type of tissue required for the scheduled surgery. Héma-Québec is responsible for making the requested product available by the time required.

### Number of donors (eye tissue), 2008–2014



Source: Héma-Québec

The Quebec waiting list for cornea transplants has been cut by more than half since 2011. In two years, it dropped from 704 to 328. This progress was due to a new procurement process and cooperation with our eye bank partners in Montreal and Quebec City.

### Patients awaiting cornea transplants, 2011–2013

	NUMBER OF PATIENTS ON WAITING LIST				SHORTENING OF WAITING LISTS (%)	
	AS OF 2/8/2011	AS OF 11/1/2011	AS OF 4/30/2012	AS OF 3/20/2013	4/30/2012 TO 3/20/2013	2/8/2011 TO 3/20/2013
Montreal*	506	380	360	207	▼ 43%	▼ 59%
CUO-QC**	198	156	131	121	▼ 8%	▼ 39%
<b>Total</b>	<b>704</b>	<b>536</b>	<b>491</b>	<b>328</b>	<b>▼ 33%</b>	<b>▼ 53%</b>

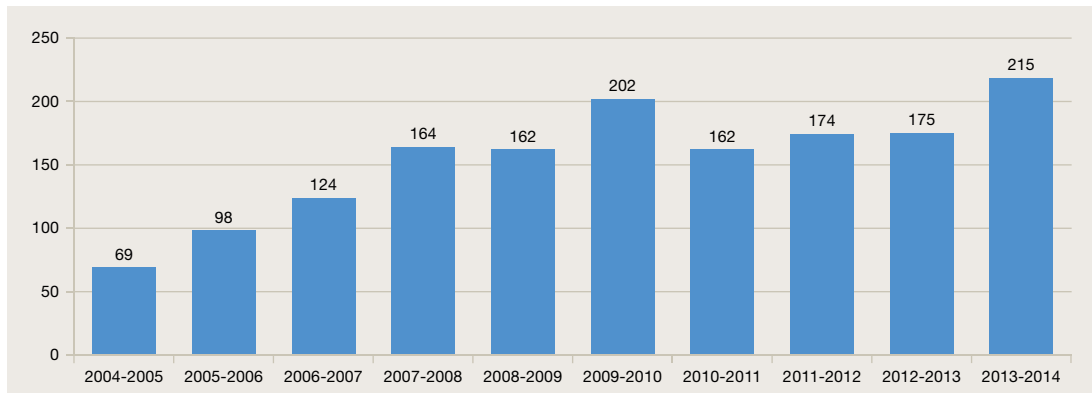
\*Montreal: Quebec Eye Bank in Montreal

\*\*CUO-QC: Centre universitaire d'ophtalmologie du CHU de Québec, Hôpital Saint-Sacrement site

### Other tissues (heart valves, skin, bone, and tendons)

Although Héma-Québec is Quebec’s only distributor of eye tissue, such is not the case for other types of tissue. Whether for heart valves, skin, tendons, or bone tissue, hospitals can use any supplier to meet their needs. Héma-Québec’s mission, it should be noted, is to efficiently meet the needs of the Quebec population for optimal-quality human tissues.

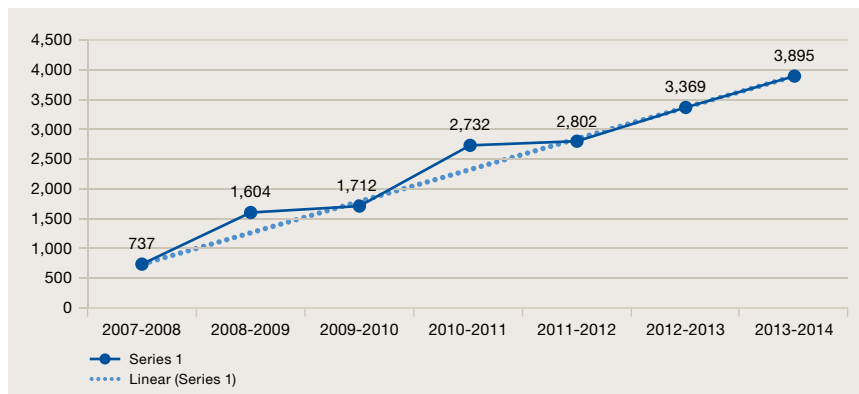
#### Number of donors (heart valves, skin, bone, and tendons), 2004–2014



Source: Héma-Québec

The use of human tissue for grafting has grown steadily in recent years. The emergence of new surgical techniques, an aging population, and new therapeutic indications for certain types of tissue grafts are just a few of the factors that have contributed to this growth.

#### Distribution of tissues by Héma-Québec, 2007–2014



Source: Héma-Québec

Héma-Québec makes an ongoing effort to promote the various products and services it provides to the province’s hospitals and is pleased that there has been a steady, marked increase in demand for grafts along with a high rate of user satisfaction.



## Tissue transplants

In an allograft, or allogeneic transplant, a patient receives a graft of tissue from another person.

In most cases, the purpose of the tissue transplant is to improve recipients' quality of life, although in the case of heart or skin tissue, it may well help save their life.

Allografts are life-changing for thousands of patients. Some examples of allografts are provided below, according to surgical specialization.

**Eye allograft.** Eye tissue is removed from a deceased donor, evaluated and preserved for varying periods (14 days to one year). Eye tissue transplants can be used to treat a variety of pathological conditions, such as these:

- Keratoconus and bullous keratopathy – Cornea replacement
- Corneal perforation – Use of a part of the cornea or a whole cornea
- Glaucoma (surgery) – Valve implant that must be covered by a sclera
- Pterygium or an eye tumour (ablation) – Use of lamellae (frozen tissue) to rebuild the eye surface

**Cardiac allograft.** The aortic or pulmonic valves and their respective arteries are removed from a deceased donor, processed and cryogenically preserved for up to five years. Allografts are implanted to correct certain congenital heart defects:

- Some forms of tetralogy of Fallot
- Complete transposition of the great arteries (TGA) with ventricular septal defect (VSD) and subpulmonary stenosis or pulmonary atresia (Rastelli procedure)
- Severe pulmonary valve stenosis
- Aortic valve stenosis

**Skin allograft.** Skin allografts are removed from a deceased donor, processed and cryogenically preserved for up to five years.

Skin allografts can be used to treat

- Severe burns – The graft serves as a temporary dressing to reduce fluid loss and as a barrier against infection
- Other conditions (e.g., toxic epidermal necrolysis)

**Bone or tendon allograft.** Bone and tendon allografts are removed from a deceased donor, processed and cryogenically preserved for up to five years. They can be used for

- Hip revision surgery
- Knee revision surgery
- Replacement of a massive bone segment in certain osteosarcoma cancer cases
- Replacement of a tendon after trauma

# LEGISLATIVE FRAMEWORK

An Act to Facilitate Organ and Tissue Donation (SQ 2010, c. 38) entered into effect on February 28, 2011, amending the following three acts:

1. Act Respecting Labour Standards (CQLR, c. N-1.1)
2. Act Respecting the Régie de l'Assurance Maladie du Québec (CQLR, c. R-5)
3. Act Respecting Health Services and Social Services (CQLR, c. S-4.2)

This document does not address the Act Respecting Labour Standards or the Act Respecting the Régie de l'Assurance Maladie du Québec because they do not apply to the directors of professional services (DPSs) at health-care establishments and because this framework only covers donation on death, whether imminent or recent.

Certain provisions of the Civil Code of Québec (CQLR, c. C-1991) apply to organ and tissue donation. These will be discussed below. The potential donor's consent can be recorded with the Régie de l'Assurance Maladie du Québec (RAMQ), which must maintain a registry (since 2011), or with a notary who must inform the Chambre des Notaires du Québec, which has also maintained a consent and refusal registry since 2005. Potential donors may also indicate their consent on the back of their health insurance card by signing and dating the sticker and affixing it in the space provided.

No matter what option they choose, potential donors may revoke their consent without having to provide a reason. If a donor has chosen more than one option, the one made most recently must be used. In the event potential donors' wishes are unknown and they are unable to give their consent, alternative consent may be obtained from a person indicated in article 15 of the Civil Code of Québec, provided the order of priority set out in that article is followed.

Section 204.1 of the ARHSSS defines the donor identification and referral responsibilities of DPSs of establishments that operate general and specialized hospitals (GSHs). Subject to consent by the potential donor or someone representing the potential donor, the section imposes the obligation to send any required medical information about the potential donor and the organs or tissues that may be removed, as applicable, to Transplant Québec (organs) or Héma-Québec (tissues). Moreover, the establishment must have an organ or tissue donation procedure for the DPS to follow. Establishments should refer to the Standardized Organ Donation Procedure and Standard Tissue Donation Procedure that were developed by organ and tissue donation partners.

■ Act Respecting Health Services and Social Services, CQLR, c. S-4.2

ASPECTS OF THE LAW	SECTION	WORDING	STAKEHOLDERS
<b>Diligent identification and referral of potential donors in situations of imminent or recent death</b>	<b>204.1</b>	When informed of the imminent or recent death of a potential organ or tissue donor, the director of professional services of an institution operating a general and specialized hospital shall diligently:	<b>GSH</b> <ul style="list-style-type: none"> <li>• DPS</li> <li>• Physicians</li> <li>• Health-care professionals</li> </ul>
<b>Verification of consent for organ or tissue removal</b>	<b>(1)</b>	verify, with one of the organizations that coordinate organ or tissue donations and are designated by the Minister under section 2.0.11 of the Act respecting the Régie de l'assurance maladie du Québec (Chapter R-5), whether the potential donor's consent for the post-mortem removal of organs or tissues is recorded in the consent registries established by the Ordre professionnel des notaires du Québec and the Régie de l'assurance maladie du Québec, in order to determine the donor's last wishes expressed in this regard in accordance with the Civil Code; and	<ul style="list-style-type: none"> <li>• <b>Transplant Québec</b> (organ donation)<sup>10</sup></li> <li>• <b>Héma-Québec</b> (tissue donation)</li> <li>• <b>RAMQ</b> (registry)</li> <li>• <b>Chambre des notaires du Québec</b> (registry)</li> </ul>
<b>Communication of medical information</b>	<b>(2)</b>	send to such an organization, if the consent has been given, any necessary medical information concerning the potential donor and the organs or tissues that may be removed.	<b>GSH</b> <ul style="list-style-type: none"> <li>• DPS</li> <li>• Physicians</li> <li>• Health-care professionals</li> <li>• Medical records</li> <li>• <b>Transplant Québec</b> (organ donation)</li> <li>• <b>Héma-Québec</b> (tissue donation)</li> </ul>
<b>Family support</b>			<b>GSH</b> <ul style="list-style-type: none"> <li>• Care team</li> <li>• Organ donation liaison nurse or resource nurse (where applicable)</li> <li>• <b>Clinical coordinator/advisor with Transplant Québec</b> (organ donation) – to support teams</li> <li>• <b>Coordinator with Héma-Québec</b> (tissue donation)</li> </ul>

<sup>10</sup> Transplant Québec and Héma-Québec are designated by Order of the Minister of Health and Social Services concerning the list of organizations ensuring the coordination of organ or tissue donations, M.O. 2011 004: [www.ramq.gouv.qc.ca/SiteCollectionDocuments/citoyens/en/autres/arrete-ministeriel-don-organes-en.pdf](http://www.ramq.gouv.qc.ca/SiteCollectionDocuments/citoyens/en/autres/arrete-ministeriel-don-organes-en.pdf)

■ Civil Code of Québec, CQLR, c. C-1991

ASPECTS OF THE LAW	SECTION	WORDING	STAKEHOLDERS
<b>Consent given by</b> – Adult – Minor 14 or over – Holder of parental authority (minor under age 14)	43	A person of full age or a minor 14 years of age or over may, for medical or scientific purposes, give his body or authorize the removal of organs or tissues therefrom. A minor under 14 years of age may also do so with the consent of the person having parental authority or of his tutor. These wishes are expressed verbally before two witnesses, or in writing, and may be revoked in the same manner. The wishes expressed shall be followed, unless there is a compelling reason not to do so.	<ul style="list-style-type: none"> <li>• <b>Adult</b></li> <li>• <b>Minor 14 or over</b></li> <li>• <b>Holder of parental authority</b> (minor under age 14)</li> <li>• <b>GSH</b></li> <li>• <b>RAMQ</b> (registry)</li> <li>• <b>Chambre des notaires du Québec</b> (registry)</li> </ul>
<b>Consent given by a third party</b>	44	A part of the body of a deceased person may be removed, if the wishes of the deceased are not known or cannot be presumed, with the consent of the person who was or would have been qualified to give consent to care. Consent is not required where two physicians attest in writing to the impossibility of obtaining it in due time, the urgency of the operation and the serious hope of saving a human life or of improving its quality to an appreciable degree.	<p><b>If the wishes of the deceased are not known</b>, his or her legal representative as defined in art. 15 of the CCQ</p> <p><b>In the absence of a representative</b>, a person, by order of priority, identified in art. 15 of the CCQ</p> <p><b>In emergency situations</b>, two physicians</p>
<b>Attestation of death and removal of donations or tissues</b>	45	No part of the body may be removed before the death of the donor is attested by two physicians who do not participate either in the removal or in the transplantation.	Two physicians who do not participate in the removal or transplantation

■ Act Respecting the Determination of the Causes and Circumstances of Death, CQLR, c. R-0.2

ASPECTS OF THE LAW	SECTION	WORDING	STAKEHOLDERS
<b>Cause of death</b> • Not established by the physician • As a result of negligence • In obscure or violent circumstances	34	Every physician who certifies a death for which he is unable to establish the probable causes or which appears to him to have occurred as a result of negligence or in obscure or violent circumstances shall immediately notify a coroner or peace officer.	<ul style="list-style-type: none"> <li>• Physician</li> <li>• Coroner</li> <li>• Peace officer</li> <li>• <b>Transplant Québec</b> (organ donation)</li> <li>• <b>Héma-Québec</b> (tissue donation)</li> </ul>

Under this section, an establishment may not proceed with removing an organ or tissue from a deceased person until the coroner has authorized it, subject to consent obtained according to the provisions of the Civil Code (**the deceased person having given consent while alive, or in the absence of such consent, a legal representative, and if no legal representative has been appointed, a person, by order of priority, identified in article 15 of the Civil Code**).

# GUIDING PRINCIPLES

A number of principles stemming directly from the values set out above may prove useful in guiding the actions of health-care establishments and providers:

- Consult and cooperate with other stakeholders to promote an increase in organ and tissue donations to meet demand.
- Acknowledge the shared responsibility and interdependence between different organizations involved in various organ and tissue donation processes and ensure coordination and communication between partners.
- Make sure services and resources are accessible and available when needed in the organ and tissue donation processes.
- Recognize the role of each establishment according to the nature of its activities, in line with the population it serves.<sup>11</sup>
- Foster knowledge sharing between donation organizations and establishments and support research in the field with the support of Transplant Québec or Héma-Québec for the purpose of developing and implementing best practices.

<sup>11</sup> Organ donation activities are discussed below separately for identification, procurement and transplantation centres. For tissue donation, each establishment may be considered a potential procurement centre.

# ORGANIZATIONAL ARRANGEMENTS

Establishments must support clinical teams in offering required organ and tissue donation services. It is important that management adopt an organizational vision and culture promoting organ and tissue donation to guide decision making on how services are to be organized within the establishment. A commitment to organ and tissue donation from all levels of management together with the active involvement of physicians and other health-care professionals will help foster such an organizational culture.

Establishments must also meet Accreditation Canada standards for safe, high-quality care and services. Monitoring and evaluating outcomes of the organ and tissue donation processes will allow the necessary adjustments to reach Quebec's organ and tissue donation targets. To that end, it is highly desirable that outcomes should be monitored by clinical teams directly, along with management teams and boards of directors.

The organizational policies to be followed within establishments to support the organ and tissue donation processes are set out below. Some are similar while others present several differences.

## MANAGEMENT COMMITMENT

- Adopt a common and shared vision within the establishment so that clinical teams begin taking organ and tissue donation concerns into account as a matter of course.
- Develop an organizational culture that promotes organ and tissue donation.
- Align actions with Safety of Human Cells, Tissues and Organs for Transplantation Regulations and Accreditation Canada standards for donation or transplantation, as applicable.
- Incorporate the organ and tissue donation vision and culture into decisions about the organization of services.
- Ensure engagement from clinical, medical and administrative teams in organ and tissue donation.
- Monitor organ and tissue donation outcomes using a continuous improvement approach to quality and clinical and organizational performance measurement.
- Build partnerships with organ and tissue donation organizations and with other establishments when required.
- Craft an organ and tissue donation communication plan that incorporates the following:
  - An awareness campaign targeting employees and physicians in cooperation with Transplant Québec and Héma-Québec to encourage registration with consent registries
  - Increased awareness among clinical staff
  - Providing information about the organ and tissue donation tools that are available
  - Local and regional awareness and education initiatives on donation, transplantation and grafting

## MANAGEMENT TEAM'S ROLES AND RESPONSIBILITIES

The management team assumes shared responsibility for the establishment's organ and tissue donation activities and for factoring them into how services are organized.

The ARHSSS assigns specific responsibilities to the DPS, who must be supported by the management team.

The DPS's specific responsibilities include the following:

- Ensuring the application of section 204.1 of the ARHSSS according to the organ donation procedure and tissue donation procedure (See *Legislative framework*, p. 24.)
- Ensuring the proper functioning of the organ and tissue donation committee in cooperation with the establishment's other divisions
- Work in conjunction with the CPDP in its role in assessing the quality of procedures

Establishments must implement mechanisms and allocate the necessary resources to support organ and tissue donation activities at all levels. Identifying one or more proponents within the establishment will make it easier to monitor these activities. These are some of the key measures to be implemented first:

- Application of the organ donation procedure and tissue donation procedure
- Training of clinical and medical teams, especially those working within critical care units
- Formation of an organ and tissue donation committee
- Use of monitoring and feedback mechanisms with an eye toward continuous improvement, with the help of the records department

Organ and tissue donation policies and procedures are designed to support the DPS and clinical teams in their efforts to identify as many potential donors as possible, as well as in the following steps: referral to the appropriate designated organization, communication of the diagnosis and prognosis to the family, proposal of the donation option, assessment and eligibility of the donor and removal of the organs or tissues.

The management team must disseminate these procedures and ensure they are followed by all clinical teams concerned.

## TRAINING OF CLINICAL TEAMS

**The training of clinical teams is key to achieving desired organ and tissue donation outcomes.** The management team must therefore plan appropriate training activities to support them in this regard. It is also important to ensure new employees are trained when they are hired. This applies to all critical care staff (e.g., nurses, respiratory therapists, physicians, social workers and spiritual care advisors).

Continuous training activities must be planned to ensure that organ and tissue donation knowledge by clinical teams is up to date.

Transplant Québec and Héma-Québec can contribute actively to these training activities in a variety of ways. Establishments can contact these organizations for support and assistance.

## ORGAN AND TISSUE DONATION COMMITTEE

Organ and tissue donation committees play a key role in ensuring the advancement of donation within establishments.

The specific responsibilities of DPSs are set out in the ARHSSS. DPSs cannot be expected to know from day to day or at any given time how things stand in terms of identifying potential organ and tissue donors, referrals to Transplant Québec or Héma-Québec, donor maintenance and organ and tissue procurement. This points to the need for an interdisciplinary organ and tissue donation committee to support the DPS and management team in performing their duties.

Every establishment should therefore have an organ and tissue donation committee that reports directly to the DPS or a designated representative. Depending on circumstances and specific needs, the committee's responsibilities may be delegated to another existing committee related to critical care (emergency, intensive care, heart units), given the nature of organ and tissue donation activities. The committee's main duties are to

- Promote organ and tissue donation within the establishment
- Promote the training of hospital staff, especially doctors, nurses and respiratory therapists working in critical care
- Monitor and evaluate the professional activities that affect steps in the organ donation procedure and tissue donation procedure
- Analyze performance and quality indicator data
- Make recommendations to resolve problems that affect steps in the organ donation procedure and tissue donation procedure, specifically by suggesting ways to optimize the process and make ongoing improvements
- Produce an organ and tissue donation progress report at least once a year for management listing key challenges and setting out appropriate recommendations
- Ensure recommendations are implemented and evaluate the results

### Composition and operation

In addition to the DPS or designated representative, the committee should include professionals working in the critical care departments where most of the potential organ and tissue donors are located. A member of the executive board of the CPDP should also join the committee. It is also recommended that the Transplant Québec clinical coordinator/advisor, a Héma-Québec representative and, where applicable, an organ and tissue donation liaison nurse or resource nurse actively participate on the committee to provide as much support as possible. An archivist may also help the committee in its work as needed.

The number of committee members and meetings may vary by establishment according to the volume and nature of organ and tissue donation needs.



## FOLLOW-UP AND FEEDBACK MECHANISMS

To ensure continuous improvement, it is important to have monitoring and feedback mechanisms in place to measure outcomes and make any necessary changes. Establishments must also take care to offer quality services that meet standards of excellence. In this regard they must meet Accreditation Canada standards for organ and tissue donation.

Accreditation Canada recognizes the importance of properly organizing services to achieve the best possible results in organ donation and tissue donation. Organ and tissue donation standards for deceased donors have been covered by the Accreditation Canada program since 2010. The applicable standards are as follows:

- Organ and Tissue Donation Standards for Deceased Donors
- Critical Care (Standard 8)
- Emergency Department (Standard 9)
- Organ and Tissue Transplant Standards

Transplant Québec offers support services to guide establishments through the accreditation process. It has also developed a reference document, *Soutien et accompagnement des établissements de santé et de services sociaux du Québec relativement aux normes d'Agrément Canada* [support and assistance for Quebec health and social service agencies with respect to Accreditation Canada standards].

On the tissue donation side, Héma-Québec can provide information on regulatory requirements so establishments can be sure they conform to Accreditation Canada's standards.

Furthermore, establishments must have access to compilation tools to measure and evaluate outcomes. Dashboards are useful for monitoring outcomes and supporting the donation committee and management team with regard to organ and tissue donation organizational matters. Annual progress reports for the board of directors are also recommended.

Transplant Québec operates an information system to document organ donation activities, specifically through the organ donation quality indicators project. Pilot projects in several establishments have demonstrated its worth. The information system provides establishments with quick information on organ donation outcomes in their area so they can evaluate their performance and adjust their strategies accordingly.

# SPECIAL POINTS TO TAKE INTO ACCOUNT

The services available and how they are delivered are not the same for organ donation and tissue donation. Establishments must therefore consider the specific characteristics of each donation type and adapt services accordingly.

The information below lists points to consider in organ and tissue donation. That way clinical teams can follow clear guidelines when interacting with patients and their families in situations of imminent or recent death.

In addition, both Transplant Québec and Héma-Québec support establishments by guiding them through the continuum of care to be provided in organ and tissue donation activities.

# ORGANIZATION OF ORGAN DONATION SERVICES

A range of services must be accessible and available within the identifying establishment, usually in close cooperation with a second establishment (the procurement centre) and potentially a third (the transplantation centre). For a successful organ donation process, services must be organized so as to take the following special factors into account:

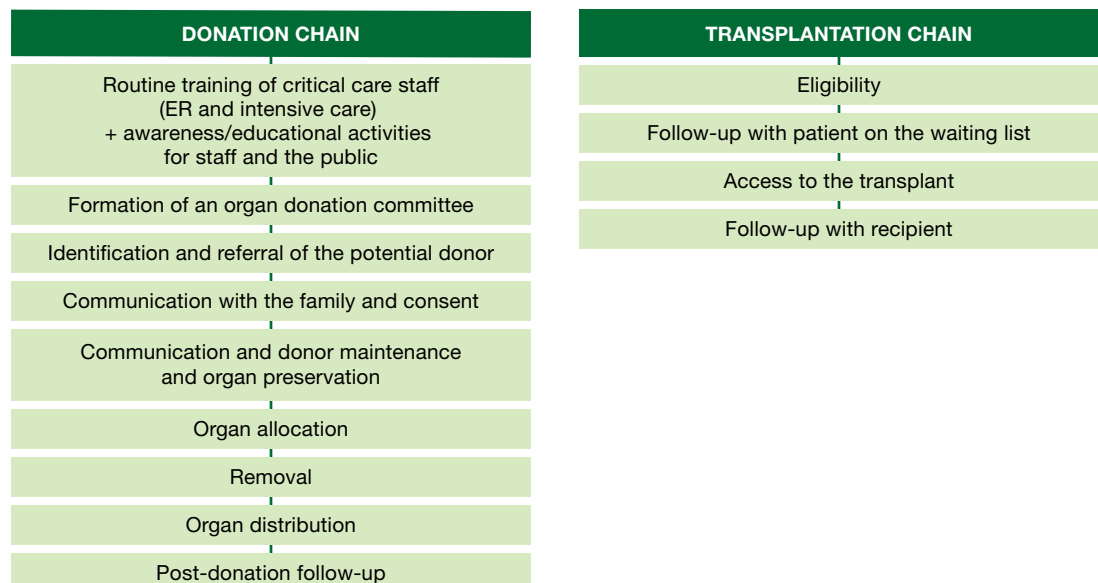
- The limited number of annual donors overall and per establishment
- How donors are identified and maintained
- How the organ donation proposal is presented to the family
- Timely access to a bed in intensive care
- Timely access to the operating room, often after coordinating multiple surgical teams from a number of specialties
- Training of attending teams in critical care units (on hiring, during onboarding in a new department, and as part of continuous training)

## Facts on the organ donation process

- The process varies in terms of length (due to the unexpected nature of organ donation, which usually occurs in the emergency room or intensive care), occurs when the family is in a state of shock, and requires the involvement of a larger number of people.
- When an organ is donated after death, 100 to 150 people are involved.
- Organ donation can happen anytime, 24/7.
- Detailed logistical procedures must be followed to ensure success.
- The number of donors may vary from 0 to 10 in a single week for all of Quebec.
- Ten donors can result in 30 to 40 transplants, requiring 40 to 50 intensive care beds plus operating rooms for all these cases.

## ROLES AND RESPONSIBILITIES OF VARIOUS PLAYERS

### Organ donation and transplantation chain



Source: Transplant Québec

The organ donation and transplantation chain is only as strong as its weakest link. Ongoing mobilization of stakeholders will facilitate efforts required at all levels. This requires that establishments make a concerted effort with Transplant Québec to ensure they are fulfilling their responsibilities every time it is required, from identification to organ removal, and for every donor.

■ Centres by activity type and establishment categories as they relate to the steps in the organ donation chain

CENTRE BY ACTIVITY TYPE	ESTABLISHMENT CATEGORIES		COMMENTS	STEPS IN THE ORGAN DONATION AND TRANSPLANTATION CHAIN
<p><b>Identification centres</b></p> <p><i>Activities in the donation chain may be carried out by the identification or procurement centre, or by both at the same time</i></p>	All establishments whose missions involve general and specialized care		Centres with an emergency room and the ability to offer intensive care	<ul style="list-style-type: none"> <li>• <b>Identification</b> of potential organ donor</li> <li>• <b>Referral</b> of potential organ donor to Transplant Québec</li> <li>• <b>Communication</b> of diagnosis/prognosis to family</li> <li>• <b>Proposal</b> of the organ donation option</li> <li>• Donor <b>evaluation and maintenance</b></li> </ul>
<p><b>Procurement centres</b></p> <p><i>All procurement centres are identification centres</i></p>	<p><b>PRACTICES RELATED TO NDD AND DCD</b></p> <p>(See App. 2, p. 66.)</p>	<p><b>PRACTICES RELATED TO DCD ONLY</b></p> <p>Establishments that can proceed accordingly</p>	<p>Currently only a handful of establishments in Quebec remove organs.</p> <p>For DCD cases, Transplant Québec may perform the removal in an establishment with which it has an agreement.</p>	<p>In addition to the steps set out above:</p> <ul style="list-style-type: none"> <li>• Organ <b>removal and preservation</b></li> </ul>
<p><b>Transplantation centres</b></p> <p><i>As a general rule, transplantation centres are identification and procurement centres</i></p>	(See App. 2, p. 66.)		<p>The number of transplant programs in Québec is as follows:</p> <ul style="list-style-type: none"> <li>- 7 for the kidneys (including 2 pediatric programs)</li> <li>- 3 for the heart</li> <li>- 2 for the liver (pediatric)</li> <li>- 1 for the lungs</li> </ul>	<p>In addition to the steps set out above:</p> <ul style="list-style-type: none"> <li>• <b>Evaluation of eligibility</b> of patient on a transplant waiting list</li> <li>• <b>Transplantation</b></li> <li>• <b>Follow-up</b> with recipient</li> </ul>

It is also important to support the organization of services at the regional and interregional levels. It may be necessary to establish corridors of service in order to pool resources. Factors to consider in organizing organ transplant services will be covered in further detail given the specific nature of transplant activities. Only eight establishments with highly specific programs are affected.

A number of community partners and associations are also involved in the organ donation process.

## ORGANIZATION OF SERVICES

Organization of services must be taken into account according to type of activity and establishment category. The points to consider will vary depending on whether the establishment is a potential donor identification centre, procurement centre or transplantation centre. This framework covers donor identification, referral and maintenance, and organ procurement for these establishments. In addition, the DCD protocol is set out so that establishments that do not currently perform organ removal can evaluate the impacts associated with that particular activity.

**Organ donation requires working in partnership and poses a networking challenge.** Establishments must therefore identify partners and specify corridors of service and coordination processes and procedures necessary for the proper conduct of activities in cooperation with Transplant Québec.

### EMERGENCY SERVICES (AND OTHER CARE UNITS)

- Follow organ donation procedures, particularly for identification, referral and family communication.
- After identifying a potential donor, verify the donor's eligibility with Transplant Québec before transferring the donor to the establishment's intensive care unit.
- Make sure physicians and clinical teams have access to equipment (e.g., respirators).
- Maintain the hemodynamic stability of the potential donor.
- Take the necessary steps in organizing the donation: applicable clinical examinations within the required time frames, transferring the patient to another establishment if needed, etc.
- Facilitate and support these activities.
- Support the family throughout the process and avoid proposing the donation option in the emergency room whenever possible.

### INTENSIVE CARE (INCLUDING THE HEART AND NEONATOLOGY UNITS)

- Follow all steps in the organ donation process.
- Make sure the potential donor is admitted to intensive care (access to a bed and to equipment such as a respirator).
- Maintain the hemodynamic stability of the potential donor.
- Take the necessary steps in organizing the donation: applicable clinical examinations within the required time frames, transferring the patient to another establishment if needed, etc.
- Declare brain death according to current protocols.
- Perform clinical exams to confirm neurological death or donation after cardiocirculatory determination of death, taking into account the provisions of article 45 of the Civil Code of Québec. (See *Legislative framework*, p. 26.)
- Help evaluate the donor and the quality of the organs.
- See to it that the family is supported throughout the process.

## DIAGNOSTIC SERVICES

- Perform the required analyses and examinations quickly: laboratories (serology and virology in particular), pathology (biopsy), medical imaging (general radiography, tomodensitometry, angiography, coronary angiography, ultrasound, etc.) and histocompatibility laboratory.
- Ensure access to other diagnostic services when required (electrophysiology, etc.).

If a diagnostic service is not available or if it cannot be performed in an establishment, the examination will be done at the procurement centre.

## MEDICAL SERVICES

- Take into account the medical specialties brought into play in the donation process and assess the impacts on their clinical practice (imaging, pathology, surgery, neurology, cardiology, pulmonology, etc.).
- Encourage physicians to get involved in the organ donation process:
  - Send the required information on the organ donation process to the physicians working in the establishment who may be brought in at various times in the process.
  - Support and encourage physician and resident training.
  - Encourage physician participation on the organ and tissue donation committee.
- Ensure that the CPDP controls and properly assesses the quality of the medical and pharmaceutical procedures involved in the organ donation process.
- For procurement centres only, grant privileges to physicians from other establishments or provinces.

## PHARMACY DEPARTMENT

- Support medical teams and clinics in maintaining donors and during organ (heart and lung) recruitment procedures in terms of pharmaceutical services and care, with the aim of achieving optimal organ function to increase the number of transplantations.

## OPERATING ROOM

- Make the operating room available for organ removal on a flexible basis, taking into account the availability of rooms, clinical teams and procurement physicians.
- Assess the specific impacts associated with DCD (death of the patient in the operating room when treatment or end-of-life care is stopped, with the family usually in attendance) and take them into account when implementing this service.

## INTERESTABLISHMENT TRANSFERS

- Promote collaboration between establishments, primarily those offering specialized neurology, neurosurgery and traumatology services and the establishments that do not. It is important to keep the number of transfers for organ donation purposes to a minimum and remember their impact on loved ones. Transplant Québec seeks to optimize donor movement in order to minimize the number of patient transfers in the donation process.

For example, when a patient meets the identification criteria and must be transferred to another establishment for a specialty consultation, it is recommended that the patient remain at the establishment he or she has been transferred to, even if treatment is not possible, when the patient is likely to be a potential organ donor. The donation process can thus continue at that establishment. Such methods avoid point-less transfers and reduce the inconvenience and cost. If a patient needs to return to the original establishment (e.g., patient's death, organ donation ineligibility or the family's wish), Transplant Québec can provide financial aid for the transfer, if needed. (See Appendix 4, under Financial support, p. 68.)

- Proceed as prearranged with the establishments involved, especially as concerns donor management (aspects of donor maintenance or organ procurement).
- Schedule the staff needed to transfer the donor (intubated patient) to a procurement centre. For organ removal, ensure the donor is transferred to the procurement centre selected by Transplant Québec.

## MEDICAL RECORDS

- Disclose information from the record as needed.
- Help collect data for the Transplant Québec performance indicators, primarily by reviewing the records of people who died in critical care units, in order to provide information that can be used when assessing the quality of the establishment's organ donation process.
- Serve on the donation committee at least once a year or as needed.

## CLINICAL ETHICS COMMITTEE

- Assist with the implementation of organ donation practices in the establishment, as needed.
- Help to clarify the ethical aspects of organ donation and service organization.

Many organ donors are also tissue donors. In such cases, the organ donation procedure applies, and Transplant Québec transfers an organ donor who is potentially also a tissue donor to Héma-Québec, which takes charge of the tissue donation process.

## TRANSPLANT QUÉBEC SUPPORT TO ESTABLISHMENTS

### MISSION, VALUES AND STRATEGIC PRIORITIES OF TRANSPLANT QUÉBEC

Transplant Québec is the sole organization in charge of coordinating organ donation after death in Quebec. It reports to the Minister of Health and Social Services.

ORGAN  
DONATION:  
TOGETHER  
FOR LIFE

QUALITY  
SAFETY  
TRANSPARENCY  
FAIRNESS  
COLLABORATION  
CONSULTATION

#### Transplant Québec's mission

In support of Quebecers' collective effort to save lives and improve the health of people in desperate need of organs, Transplant Québec

- Coordinates the organ donation process leading to transplantation, ensuring the greatest possible availability of quality donor organs.
- Ensures that organs are allocated fairly, based on stringent ethical and clinical criteria.
- Helps improve clinical practices in institutional settings by holding hospital training and development activities and participating in donation- and transplant-related teaching and research activities.
- Acts as a catalyst to create interdependencies within the donation/transplantation system and serves as a facilitator tasked with fostering discussion and mobilizing stakeholders.
- Promotes pro-donation, pro-transplantation values of solidarity among the general public, health-care professionals and establishments concerned.

Transplant Québec is actively engaged so that the greatest number of Quebecers waiting for organs can receive transplants.

### SUPPORT PROGRAM FOR ORGAN DONATION DEVELOPMENT IN QUEBEC HOSPITALS

As part of Transplant Québec's hospital development program, each establishment offering critical care services is assigned a Transplant Québec clinical coordinator/advisor, who can help the institution develop and implement organ donation best practices.



***Roles and responsibilities of the clinical coordinator/advisor***

- Maintain ties between the establishment and Transplant Québec
- Provide assistance to create and support an organ donation committee
- Help update reference materials
- Help dispense organ donation training according to identified needs
- Cooperate with the establishment's medical records department to collect quality indicator information, in accordance with the Standardized Organ Donation Procedure
- Help organize organ donation awareness and educational activities
- Serve as an organ donation resource person
- Provide support during the Accreditation Canada process

For more information

Transplant Québec Hospital Development and Education Department

Telephone: 1-855-373-1414. Press 7 to hear the message and then press 2.

## ORGAN DONATION COORDINATION PROGRAM IN QUEBEC HOSPITALS

A team of clinical coordinator/advisors available 24/7 also coordinates the organ donation process. The entire province is served by 20 clinical coordinator/advisors based in Montreal and Quebec City.

The clinical coordinator/advisor acts as a clinical advisor and provides the support care teams need. In collaboration with physicians and all other professionals, the clinical coordinator/advisor is involved at each stage of the organ donation process:

- Identification of the potential organ donor
- Referral of the potential donor
- Management and monitoring of the donor
- Discussions with the family
- Assessment and acceptance of the donor
- Donor transfer to a procurement centre
- Assessment of transplant organs
- Organ allocation
- Organ removal and preservation
- Organ and medical team transport
- Follow-up with stakeholders, including the donor's family

Additionally, the Transplant Québec clinical coordinator/advisor oversees the master list of patients waiting for a transplant according to the rules established by the organization, as well as the post-donation follow-up for donor records.

For more information

Transplant Québec Clinical Services

Telephone: 1-855-373-1414. Press 7 to hear the message, press 4 and then press 2.

## ORGAN DONATION LIAISON AND RESOURCE NURSES

Sixteen establishments with an annual potential of 8 to 20 donors have a dedicated tissue and organ donation team made up of liaison and resource nurses.

The organ and tissue donation liaison nurse<sup>12</sup> and resource nurse<sup>13</sup> organize organ donations in cooperation with the organ and tissue donation committee, often under the direction of the establishment's professional services. They plan and organize training for health-care professionals to increase the number of referrals and the family consent rate by identifying and referring donors to Transplant Québec early in the process.

They act as resource people for the stakeholders in a shared intervention model at every stage of the organ donation process. Their role includes all of the following:

- Meet with the medical team to decide on how to approach the grieving family
- Ensure best practices are followed when the organ donation option is presented
- Offer the grieving family ongoing support
- Answer the family's questions in collaboration with the attending team

For more information

Transplant Québec Hospital Development and Education Department

Telephone: 1-855-373-1414. Press 7 to hear the message and then press 2.

## MEDICAL MANAGEMENT

Transplant Québec's operations are supported by the medical management team, which is made up of six physicians, including the medical director and the deputy medical director. Together, they form the on-call medical team that is available 24/7 to

- Make necessary medical decisions
- Guide the clinical aspect of coordination
- Act as the go-to resource people for physicians working in establishments
- Speak at information or training activities
- Help develop and revise organizational processes, policies and procedures

## TRAINING

Currently, Quebec health-care and social services professionals receive very limited preliminary training in organ donation. It is important to maintain and provide organ donation training for critical care department professionals (physicians, nurses and respiratory therapists) at each establishment, especially during orientation sessions.

<sup>12</sup> Organ and tissue and donation liaison nurses are Transplant Québec employees who work in an establishment. In 2013 there were four liaison nurses based at eight establishments (10 sites) who shared round-the-clock duty for the Montreal, Montérégie and Laval areas.

<sup>13</sup> Organ and tissue donation resource nurses are employed by the establishments where they work. Under the hospital management program administered by Transplant Québec, half of their salaries is paid by Transplant Québec and the other half by the establishment. In 2013 there were 15 resource nurses at 10 establishments (19 sites) throughout Quebec.



Transplant Québec and its team of clinical coordinator/advisors (who are all nurses), organ donation liaison nurses and physicians offer a wide variety of training activities for health-care and social services professionals, especially those working in critical care.

A number of training sessions by Transplant Québec are accredited by educational institutions or professional organizations and entitle participants to training credits.

These training sessions cover the following:

- The organ donation process, as well as the roles and responsibilities of health-care professionals
- Maintaining the hemodynamic stability of organ donors
- Breaking bad news and proposing the organ donation option

Examples of accredited training

- Standardized organ donation procedure (1 to 1.5 hours)
- Approaching and supporting the family in organ donation situations (13 hours)
- Maintaining the hemodynamic stability of organ donors (1 hour)
- Discussing and suggesting organ donation (1 hour)

Examples of non-accredited training

- Organ donation in Quebec (presentation for professionals, 3 hours)
- Organ donation in Quebec (presentation for the general public, 1 hour)

Transplant Québec offers **accredited online training** on its website. This training, developed in collaboration with the Quebec Society of Intensivists, is intended for physicians, nurses and respiratory therapists, especially those working in critical care units.

By the end of this training, the participants will know the key stages in the Standardized Organ Donation Procedure and have a better understanding of how important it is to actively participate in the donation process. Participants will be able to

- Identify their roles in the organ transplantation and donation chain
- Identify potential organ donors and refer them to Transplant Québec

Once participants have viewed the training material and passed the test, they are entitled to a **training credit**.

Transplant Québec also offers training in the form of talks at many CEGEPs and universities as part of preliminary training programs in nursing, respiratory therapy and medicine.

## DOCUMENTATION AVAILABLE TO HEALTH PROFESSIONALS AND ESTABLISHMENTS

Transplant Québec provides all health-care and social services professionals who work in critical care with reference materials that walk them through the process, from identifying potential organ donors to organ removal. Here are some examples:

- Transplant Québec website
- Standardized Organ Donation Procedure
- Standardized organ donation procedure flow chart
- Organ and Tissue Donor (OTD) binder
- Donation process checklist
- Guides, policies, protocols, procedures, and forms, including the adult and pediatric donor management guidelines

For more information

Clinical coordinator/advisor for the establishment or  
 Transplant Québec’s Hospital Development and Education Department  
 Telephone: 1-855-373-1414. Press 7 to hear the message and then press 2.

### Transplant Québec website

The Transplant Québec website, especially the Health Professionals section, provides a wealth of useful information. The section is dedicated entirely to professionals in institutional settings and is designed to explain the organ donation process and simplify their work.

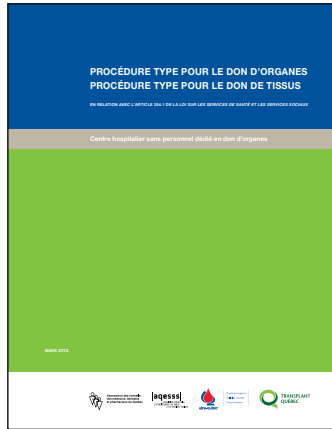
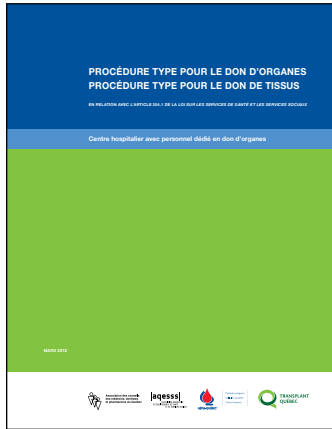
[www.transplantquebec.ca](http://www.transplantquebec.ca)



## Standardized Organ Donation Procedure

Version for hospitals with dedicated organ donation personnel

Version for hospitals without dedicated organ donation personnel

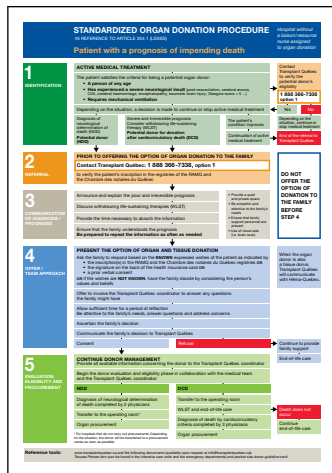
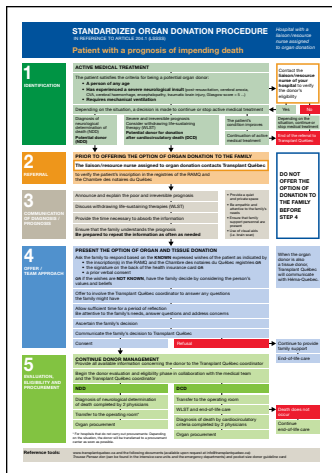


The purpose of this procedure is to support organ and tissue donation in establishments with a view to better identification and more systematic referrals of potential organ donors. Both versions (with and without dedicated organ donation personnel) are intended primarily for DPSs, members of organ and tissue donation committees and critical care professionals. The procedure goes a long way to facilitating their work, while also improving outcomes in the establishment and ensuring services meet Accreditation Canada's new (deceased donor) organ donation standards.

## Standardized organ donation procedure flow chart

Version for hospitals with dedicated organ donation personnel

Version for hospitals without dedicated organ donation personnel



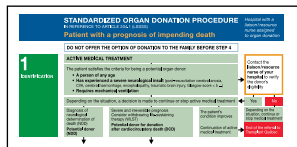


## Organ Donor and Tissue Donor (OTD) binder

The Organ and Tissue Donor binder guides the care team through every stage of the organ donation process. The binder has been distributed to all hospitals and must be available in all critical care departments. It contains seven chapters on the following topics:

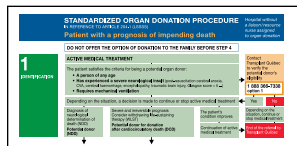
- Identification of potential organ donors
- Supporting and approaching grieving families
- Neurological determination of death (NDD) and donation after cardio-circulatory death (DCD)
- Consent forms
- Assessment and management of potential donors
- Donor transfer to a procurement centre
- Act to Facilitate Organ and Tissue Donation, in force since February 2011

Critical care teams do not have to worry about updating this tool because this is the responsibility of each establishment’s clinical coordinator/advisor.



## Donation process checklist

This pocket reference guides critical care professionals through the organ donation process. The checklist is based on the Standardized Organ Donation Procedure. It provides a great deal of valuable information on the organ donation process.



Copies of the checklist are available from the establishment’s Transplant Québec clinical coordinator/advisor or the hospital development and education department.

## Guidelines, policies, protocols, procedures and forms

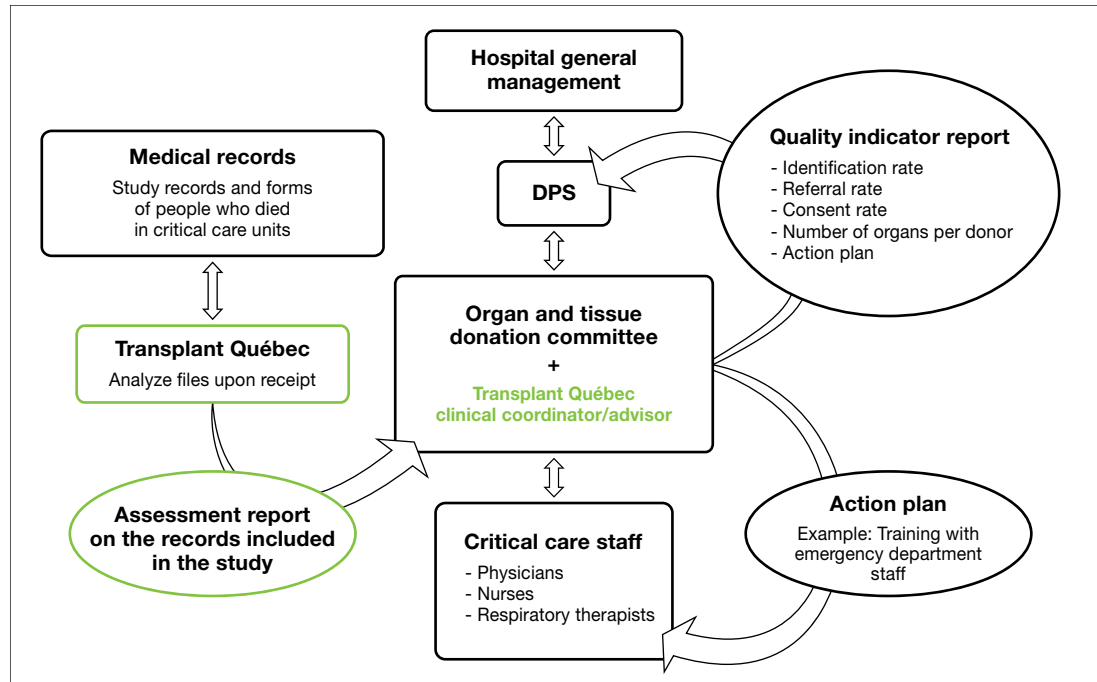
Transplant Québec provides numerous guides, policies, protocols, and procedures for physicians and health-care professionals. For instance, the Health Professionals section of the organization’s website includes the following resources:

- Organ Donor Assessment and Management Guidelines – Adults
- Protocole de recrutement cardiaque et pulmonaire [cardiac and pulmonary recruitment protocol]
- Organ Donor Assessment and Management Guidelines – Pediatrics
- Protocole type destiné au don d’organes après décès cardiocirculatoire (DDC) [standardized protocol for donation after cardiocirculatory death]

The organ donation clinical procedures and forms are also available on the Transplant Québec website at [www.transplantquebec.ca/en/professionnels](http://www.transplantquebec.ca/en/professionnels).

## PERFORMANCE INDICATORS

### Organization chart with organ donation quality indicators



Source: Transplant Québec

Four key performance indicators set out and described in the Standardized Organ Donation Procedure are used to monitor organ donation in the establishment.

#### ■ Establishment with dedicated organ donation personnel

These indicators from the organ donation quality indicator (ODQI) system are available from the organ donation liaison or resource nurses working at the establishment and are obtained through the retrospective study of the records of people who died primarily in the establishment's critical care departments.


#### ■ Establishment without dedicated organ donation personnel

The ODQI system is available to provide quality indicators first to establishments without dedicated organ donation staff.

With the participation of the records department of establishments with general and specialized care missions, the new system draws on the organ donation work CMQ has conducted for more than 10 years.

Health-care professionals, DPSs and organ and tissue donation committees will find the data very useful in assessing progress in organ donations and, as needed, developing action plans to address identified problems.

The four (4) performance indicators are as follows:



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**Rapport de situation sur le don d'organes pour le directeur des services professionnels**

Centre hospitalier : \_\_\_\_\_

Période étudiée : \_\_\_\_\_

Nombre de décès en soins critiques :      Urgence : \_\_\_\_\_      Soins intensifs \_\_\_\_\_      Total : \_\_\_\_\_

**Indicateurs de performance selon la procédure type pour le don d'organes**

**1 – Identification (Étape 1 de la procédure type)**

Nombre de donneurs potentiels identifiés : \_\_\_\_\_ = Taux d'identification \_\_\_\_\_ %

Nombre de donneurs potentiels total : \_\_\_\_\_

Objectif visé 100%

**2 – Références (Étape 2 de la procédure type)**

Nombre de donneurs potentiels référés: \_\_\_\_\_ = Taux de référence \_\_\_\_\_ %

Nombre de donneurs potentiels identifiés : \_\_\_\_\_

Objectif visé 100%

**3 – Communication avec la famille et consentement (Étapes 3 et 4 de la procédure type)**

Nombre de consentements au don : \_\_\_\_\_ = Taux de consentement \_\_\_\_\_ %

Nombre de familles approchées : \_\_\_\_\_

Objectif visé 80%

**4 – Nombre d'organes par donneur**

Nombre d'organes prélevés et transplantés \_\_\_\_\_ = nombre d'organes par donneur \_\_\_\_\_

Nombre de donneurs utilisés : \_\_\_\_\_

Objectif visé Donneurs après décès neurologique (DDN) 3,75      Objectif visé Donneurs après décès cardiocirculatoire (DDC) 2,75

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**Problématiques identifiées**

Étape 1 : Identification :

\_\_\_\_\_  
\_\_\_\_\_

Étape 2 : Référence :

\_\_\_\_\_  
\_\_\_\_\_

Étapes 3 et 4 : Communication avec la famille et consentement :

\_\_\_\_\_  
\_\_\_\_\_

Étape 5 : Maintien hémodynamique du donneur / nombre d'organes par donneur :

\_\_\_\_\_  
\_\_\_\_\_

**Plan d'action**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Comité de don d'organes**

Membres :

_____	_____
_____	_____
_____	_____
_____	_____

## ADVISORY COMMITTEES

Transplant Québec has a number of advisory bodies, including a medical scientific advisory committee and organ-specific subcommittees that actively participate in allocation procedure and criteria development, as well as other activities. Physicians and transplant surgeons in institutional settings also contribute to this work. Transplant Québec’s ethics committee makes recommendations on a number of issues related to the organization’s mission, in support of Quebec’s transplant and donation system. (See Appendix 4, under Transplant Québec advisory committees, p. 68.)

## SUPPORT FOR ESTABLISHMENT ORGAN AND TISSUE DONATION ACCREDITATION (DECEASED DONORS)



Since April 2010 Transplant Québec has offered establishments help with organ and tissue donation accreditation for deceased donors. Its document *Soutien et accompagnement des établissements de santé et de services sociaux du Québec* [support and assistance for Quebec health-care and social services establishments] goes over Accreditation Canada’s standards for

- Organ and tissue donation (deceased donors)
- Intensive care departments (Standard 8)
- Emergency rooms (Standard 9)

In concrete terms, Transplant Québec can

- Answer partner queries concerning Health Canada’s Safety of Human Cells, Tissues and Organs for Transplantation Regulations and the Accreditation Canada standards
- Help develop standardized documents for various aspects of standards (policies, standardized procedures and other tools)
- Assist in preparing documentation describing how roles and responsibilities set out in the standards are shared between establishments and Transplant Québec or other parties, including laboratories, with a view to signing required agreements
- Support group efforts to promote the implementation of best practices and adapt tools in cooperation with the establishments

Transplant Québec can also help establishments with living donor donation programs ensure their processes are compliant with Health Canada’s Safety of Human Cells, Tissues and Organs for Transplantation Regulations. (See Appendix 2, under Establishments offering living donor programs, p. 66.)

Transplant Québec can also act as an advisor within its field of competence, supporting hospitals with general and specialized care missions that offer organ transplantation services subject to Accreditation Canada’s Qmentum Program Organ and Tissue Transplant Standards. (See Appendix 2, under Organ transplantation centres and programs, p. 66.)

Under the mandate it received from MSSS in 2010, Transplant Québec may contact establishments to inform them of its new responsibilities and offer them support. However, Transplant Québec must intervene only as required to meet needs expressed by establishments.

For more information

Transplant Québec Compliance and Quality Department

Telephone: 1-855-373-1414. Press 7 to hear the message and then press 7.

## COMMUNICATIONS

Establishments are urged to organize informational and educational activities on organ donation and transplantation—topics in which the public has shown a great deal of interest—particularly regarding those waiting for transplants or recipients, their families and donors’ families. The media, especially at the local and regional levels, often take an interest in these issues.

Establishments often work with Transplant Québec on communications and public relations activities in the community.

Transplant Québec’s communications and public relations department will provide as much assistance as it can with communications activities in institutional and public settings.

Transplant Québec already organizes and supports a number of communications and public relations initiatives promoting organ donation to the general public and specific target audiences, particularly health-care and social services professionals, younger and older people, and soon cultural communities as well. (See Appendix 4, under Communications and public relations, p. 68.)

For more information

Transplant Québec Communications and Public Relations Department

Telephone: 1-855-373-1414. Press 7 to hear the message and then press 3.

## FINANCIAL SUPPORT FOR DONOR IDENTIFICATION AND ORGAN PROCUREMENT

Transplant Québec manages an organ donation fund for the costs incurred for deceased donors. The program provides fixed sums for the establishment’s identification and procurement centres and covers travel costs for teams, transportation costs for procured organs and for returning the body, and certain blood tests in accordance with Transplant Québec’s Identification and Payment Policy for Organ Donation from Deceased Donors. (See Appendix 4, under Financial support, p. 68.)

# ORGANIZATION OF TISSUE DONATION SERVICES

## ORGANIZATION OF SERVICES

Héma-Québec looks to general and specialized hospitals and their various departments to ensure identification and referral of all potential tissue donors. After a potential tissue donor has been referred, the Héma-Québec coordinator takes charge of the donation process and tries to minimize the impact on medical personnel. However, the cooperation of the following departments is essential for a successful donation:

- Clinical services
- Medical biology (laboratory) services, including pathology (pathology lab and morgue)
- Admissions
- Medical records
- Operating room

## RESPONSIBILITIES OF DEPARTMENTS

- Identify potential tissue donors
- Contact the Héma-Québec coordinator on duty to check the RAMQ and Chambre des notaires du Québec consent registries
- Facilitate and support these activities

## CLINICAL SERVICES

Medical staff are responsible for identifying and referring potential tissue donors according to the criteria set out in the Standardized Tissue Donation Procedure – Recent Patient Death. Recent death means a cardio-pulmonary death **without life support** that may lead to a human tissue donation.

### ■ If consent is recorded in the registries

- **Medical records**

If consent has been given, additional information on the deceased's medical history will be required so the Héma-Québec coordinator can perform a proper assessment of the potential donor's suitability. Hospital medical staff must be informed and provide the information.

- **Communication with the family**

Generally, the family and Héma-Québec speak by phone. The Héma-Québec coordinator is responsible for explaining the tissue donation process. If the family wants to leave the hospital before speaking to the coordinator, medical staff must obtain the phone number where the family can be reached within an hour of leaving.

■ **If consent is not noted in the registries or the back of the health insurance card has not been signed**

Donation must be suggested to the family and support from the Héma-Québec coordinator must be offered. If the family consents to tissue donation or has questions about the donation process, the medical professional acts as the link between the coordinator and the family. Once the coordinator has been informed of the situation, he or she will be able to take over and

- Give the family the usual explanations
- Receive consent for tissue removal
- Fill in the donor eligibility questionnaire
- Handle formalities for the transfer of the donor's body to the funeral home

■ **How are tissues procured?**

- Unlike organs, human tissues can be retrieved for several hours after blood circulations stops.
- The donor's body is treated with care and respect by a team of professionals specializing in tissue procurement. Procurement is done in specially designed facilities, in a Héma-Québec establishment, or in a hospital operating room, according to stringent procedures and in compliance with Health Canada and various recognized regulatory agency standards.

■ **When does the tissue donation process begin?**

- The donor eligibility process begins as soon as consent to tissue donation is obtained. Ideally, removal should be done as quickly as possible after death to maximize the quality of the procured tissues.

■ **Are screening tests performed during tissue donation?**

- Blood is collected to determine the donor's serological profile and ensure the recipient's safety.

■ **What is the age limit to be a tissue donor?**

The age criterion depends on tissue type:

- Cardiac tissue – Birth to 60 years
- Skin and bone tissue – 15 to 70 years
- Tendons – 15 to 60 years
- Eye tissue – 2 to 85 years

#### ■ What about confidentiality?

- The results of serological analyses remain confidential, but are sent to the public health agency if a notifiable disease is present.
- All information obtained during the donor eligibility process is protected by law.<sup>14</sup> All medical record assessment information remains strictly confidential and is used only to determine the eligibility of a potential donor.
- If tissue removal does not take place or the tissues are not used for transplantation because of information in medical or hospital records, information cannot be disclosed due to laws protecting the medical information of deceased persons.
- Some retrieved tissues may be sent to an external laboratory to be processed and conserved (Quebec eye bank in Montreal and Centre universitaire d'ophtalmologie du CHU de Québec, Hôpital Saint-Sacrement site).
- The coroner can ask to take blood samples for analysis or request copies of certain documents.
- If the donor's body is autopsied after tissue removal, the pathologist may request copies of certain documents.

#### ■ What happens to the tissues after they are removed?

- Bacteriological tests are performed on removed tissues in order to ensure a safe, optimum quality graft for the potential recipient. Tissues are processed and conserved (freezing or cryopreservation, depending on the type of tissue) until they are grafted.
- Tissues intended for transplant can be conserved for a long time without any deterioration or change in quality. However, the proper conservation methods must be used. Certain tissues can therefore be kept for up to five years. However, with the ever-growing need for transplant tissues, they are rarely kept so long.

#### ■ How many people can receive a transplant from a single tissue donation?

Depending on the type of removal and the quality of the tissues removed, a tissue donor can help up to 20 recipients. Although it can save lives just like organ donation does, in most cases, the purpose of human tissue donation is above all to maintain or improve quality of life. A heart valve donation can not only help patients return to leading normal lives, but also in certain cases eliminate the need for more complex surgery. And bone tissue donations allow recipients to maintain or noticeably improve their mobility.

#### ■ Can a potential tissue donor be excluded under certain circumstances?

Currently there is still a lack of knowledge about tissue donation, leading to shortages in potential donors identified and referred to Héma-Québec. Some typical scenarios are described below.

##### • *The donor's medical history is complicated*

"Theoretically the tissue donor's clinical picture does not appear to satisfy the donation requirements." It is better to refer the potential donor to Héma-Québec rather than refuse too hastily. The potential donor must be excluded automatically if one of the diagnoses listed in section 1 of the tissue donation procedure has been made.

<sup>14</sup> Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information, CQLR., c. A-2.1. ([www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/A\\_2\\_1/A2\\_1\\_A.html](http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=2&file=/A_2_1/A2_1_A.html))

- ***The potential tissue donor is not on a respirator***

Human tissue donation differs from organ donation in a number of ways. One important distinction is that tissues like bones, heart valves, skin, tendons, and eye tissues are much less complex structures than organs like the heart and kidneys. Unlike organs, tissues can be deprived of oxygen for a certain period of time without their quality being affected. It is therefore possible to remove them even after the donor's blood has stopped circulating. However, removal needs to take place as soon as possible to avoid the deterioration of some more fragile tissues.

- ***The potential donor is in cardiorespiratory arrest and his or her pulse does not resume***

Death must be certified. The tissue donor no longer has a heartbeat.

- ***The potential donor was found dead, rigor mortis has set in and the time of death is unknown***

Rigor mortis is not a reason to exclude a potential tissue donor. The Héma-Québec coordinator will determine with the family members, the coroner or a law enforcement officer, if appropriate, when the deceased was last seen alive. This time will be used as the time of death.

- ***The potential donor is under the guardianship of a public trustee***

A potential donor who is under the guardianship of a public trustee can be a tissue donor. The Héma-Québec coordinator will contact the trustee and conduct the usual checks:

- Presence or lack of consent
- Authorization from the trustee
- Presence or absence of a person who is familiar with the deceased's social and medical history to complete the eligibility questionnaire

- ***The potential donor is known to have MRSA<sup>15</sup> or VRE<sup>16</sup>***

A potential donor who is known to have MRSA or VRE but does not show signs of an active infection at death can undergo tissue removal. The Héma-Québec coordinator has access to a donor assessment manual and will consult his or her medical director, when appropriate.

- ***No family comes to the hospital***

The potential tissue donor is recommended to Héma-Québec whether the deceased's family is present or not. The Héma-Québec coordinator will conduct the usual checks in the existing registries and, if consent has been given, may contact the family to explain the donation process.

- ***The case comes from a coroner***

Too often still, medical staff incorrectly believe that a case from a coroner cannot end in tissue donation. For traumatic death or a death investigated by the coroner, the Héma-Québec coordinator must conduct the usual checks with the coroner, who may request an autopsy or certain assessments that will shed light on the cause of death. Generally, tissue removal is possible, and the coroner comes to an agreement with Héma-Québec on how to proceed.

- ***An autopsy is required***

This type of scenario does not prevent tissue removal at all. After the referral to Héma-Québec and consent for tissue removal has been obtained, the Héma-Québec coordinator will give the family the usual explanations and make any required arrangements with the pathologist on record.

<sup>15</sup> Methicillin-resistant *Staphylococcus aureus*.

<sup>16</sup> Vancomycin-resistant *enterococci*.

## MEDICAL BIOLOGY SERVICES

Medical biology (laboratory) services can be called upon in the following situations:

- **Availability of a blood sample.** For each donor, the Héma-Québec coordinator needs to calculate the plasma dilution. If the donor is hemodiluted, the Héma-Québec representative will contact the laboratory to find out whether a pre-infusion/pre-transfusion sample is available. If a sample is available, it may be required for the prescribed serological analyses. These analyses are contracted out to an outside laboratory.
- **Blood bank.** From time to time, the Héma-Québec coordinator may speak to a person at the hospital blood bank to obtain the exact volumes of the transfusions administered to the donor in order to calculate the plasma dilution.

## MORGUE AND PATHOLOGY LABS

A pathology lab is used for the following steps:

- Comprehensive physical examination of the donor
- Preparation of the donor for removal (shaving the surgical site, preoperative washing of the donor)
- Removal of eye tissues. This type of removal generally takes place in the setting from which the referral originates. The removal can be done in the deceased's room or in the pathology lab, depending on availability. Note that this does not apply to other types of tissues. To ensure optimum asepsis control, the removal of tissues such as skin, bone tissues, tendons and the heart for valves must be done in an operating room or a Héma-Québec establishment.

## ADMISSIONS AND MEDICAL RECORDS

The hospital's admissions or medical records services may be called upon for the reasons set out below.

### ■ Medical record assessment

A Héma-Québec staff member will need to assess the eligibility of a tissue donor who has been recommended and for whom donation consent has been obtained. To do this, the staff member will go directly to the establishment from which the referral came or will ask for certain medical records to be faxed.

#### • *On-site record assessment by a Héma-Québec staff member*

The Héma-Québec coordinator will make sure that the donor's medical record is available and will direct his or her colleague to the department in question (e.g., admissions, records, care unit). Photocopies of certain documents will be made and appended to the donor's eligibility file.

#### • *Off-site record assessment*

The Héma-Québec coordinator frequently contacts the medical records department to obtain copies of documents in the deceased's medical records. The documentation must be faxed to the number the coordinator gives the department, in compliance with the information disclosure rules for patient records.



**■ Transfer of the body to the Héma-Québec establishment or a procurement centre**

Eye tissues are usually removed at the establishment where the death has occurred. For other types of tissues, the donor's body is transferred to a Héma-Québec establishment. Families must give prior consent for body transfers. This formality is widely accepted. The Héma-Québec coordinator informs the establishment's admissions department that a funeral home is taking the donor's body and handling the transfer. After the tissue removal, the body will usually be sent to the funeral home selected by the family or to the establishment performing the autopsy, if applicable. Note that the costs associated with moving the body are covered by Héma-Québec.

**■ Review of the deceased's records in relation to the number of potential tissue donations**

Héma-Québec can ask for the medical records department's cooperation in obtaining data on the number of potential donors in the establishment.

## OPERATING ROOM

Héma-Québec has agreements with a number of establishments to use an operating room in situations where the family refuses to allow the body to be transferred to a Héma-Québec establishment.

- The procurement team uses the operating room without calling on the services of hospital staff or using hospital equipment. The Héma-Québec coordinator comes to an agreement with the operating room manager to set the removal time and decide which room will be used.
- The tissues are removed according to the planned operating schedule or the availability of the room.

If there is no agreement between the establishment and Héma-Québec, the coordinator will speak to hospital management to see whether an operating room can be used.

## HÉMA-QUÉBEC SUPPORT FOR ESTABLISHMENTS

### MISSION, VALUES AND STRATEGIC PRIORITIES OF HÉMA-QUÉBEC

Héma-Québec is the organization responsible for collecting, processing and distributing human tissues in Quebec. In October 2001, the Minister of Health and Social Services authorized Héma-Québec to expand its mission to cover human tissues. At the same time, the minister recognized Héma-Québec's expertise in human tissue processing and distribution and authorized it to take the necessary steps to carry out its new mission.

With this new mandate, Héma-Québec reformulated its mission to incorporate its new responsibilities.

Héma-Québec's mission is to efficiently meet the needs of the Quebec population for safe, optimal-quality blood and blood products, human tissues, cord blood, mother's milk, and cellular products; to develop and provide expertise and specialized, innovative services in the field of human biological products.

As in the case of blood products, Héma-Québec applies the highest standards and uses the latest technologies in order to ensure a safe and adequate supply of human tissue. Its commitment is to ensure that transplant physicians in Quebec hospitals have access to safe products for human tissue transplants.

Héma-Québec is better known for its role as the sole manager of Quebec's blood supply, but has also acted as the supplier of human tissues for transplant since December 2001. In addition to the removal of eye tissue for corneal transplants, the organization provides hospitals with skin grafts, heart valves and musculo-skeletal tissue such as tendons and bones. Quebec thus has an organization supplying safe, high quality human tissue for recipients.

Héma-Québec's business development representatives are available to publicize the human tissue products and services Héma-Québec offers and support health-care professionals who would like more information on any operational aspects, from identifying grafts to reporting adverse reactions.

For more information

Héma-Québec Business Development Manager

Telephone: 514-832-5000, ext. 385

## HOSPITAL DEVELOPMENT PROGRAM

As part of Héma-Québec's hospital development program, all establishments are entitled to support and assistance to ensure they develop and implement tissue donation best practices. In that regard, Héma-Québec's roles and responsibilities are as follows:

- Maintain ties between the establishment and Transplant Québec
- Provide assistance to create and support an organ donation committee
- Help update reference materials
- Help dispense tissue donation training according to identified needs
- Help organize tissue donation awareness and educational activities
- Serve as a tissue donation resource
- Provide support during the Accreditation Canada process

For more information

Héma-Québec Procurement Department  
Telephone: 418-780-4362, ext. 2271

## TISSUE DONATION COORDINATION PROGRAM IN QUEBEC HOSPITALS

In Quebec, coordination of tissue donation is handled by Héma-Québec's team of coordinators, who are available 24/7.

The on-call coordinator handles potential donor referrals and is able to guide medical staff through all stages of tissue donation:

- Identification of the potential tissue donor
- Referral of the potential donor to Héma-Québec
- Discussions with the family
- Assessment and acceptance of tissue donor
- Donor transfer
- Follow-up with stakeholders, including the donor's family

## AWARENESS PLAN

General and specialized care establishments have performed a review of their death records in recent years and discovered that nearly 50% of deaths could have resulted in tissue donation. In light of the great number of potential donors, Héma-Québec has developed a strategy aimed at concentrating its awareness efforts in a few targeted hospitals.

This plan suggests promotional, training, and recognition activities for medical staff based on the establishment's classification. Those establishments whose names do not appear in any category can contact Héma-Québec for information on the process.

## Classification of establishments

- Target centres
- Category 1 centres
- Category 2 centres

### ■ Target centres

In the Quebec City and Montreal areas, 14 hospitals were targeted based one or all of the following criteria:

- Proximity to Héma-Québec facilities
- Volume of referrals to Héma-Québec
- Management’s willingness to foster a tissue donation culture in the facility

#### ***Planned activities***

- Quarterly visits to care units (day, evening and night)
- Monthly calls to medical staff (day, evening and night)
- Training days – Customized or based on identified needs
- Recognition activities for medical staff – Each quarter, Héma-Québec celebrates the contribution of those who have referred potential tissue donors

#### ***List of target establishments (14 centres)***

##### **Montreal and other areas**

- Hôpital Maisonneuve-Rosemont
- Hôpital du Sacré-Cœur de Montréal
- CSSS de Laval, Hôpital de la Cité-de-la-Santé site
- CHUM, Hôpital Notre-Dame site
- CSSS du Cœur-de-l’Île, Hôpital Jean-Talon site
- CSSS du Sud de Lanaudière, Hôpital Pierre-Le Gardeur site
- CSSS d’Ahuntsic et Montréal-Nord, Hôpital Fleury site

##### **Quebec City and Chaudière-Appalaches areas**

- CHU de Québec, Hôpital de l’Enfant-Jésus site
- Institut universitaire de cardiologie et de pneumologie de Québec
- CSSS Alphonse-Desjardins, Hôtel-Dieu de Lévis site
- CHU de Québec, Hôpital Saint-François d’Assise site
- CHU de Québec, CHUL site
- CHU de Québec, Hôpital du Saint-Sacrement site
- CSSS de Beauce, Hôpital de Saint-Georges site

### ■ Category 1 centres (8 centres)

#### ***Planned activities***

- Monthly calls to medical staff (day, evening and night)
- Training days – Customized or based on identified needs
- Recognition activities for medical staff (annually) – Each year, Héma-Québec celebrates the contribution of medical staff who have referred potential tissue donors

#### ***List of Category 1 establishments***

##### **Montreal and Montérégie areas**

- CSSS de Saint-Jérôme, Hôpital régional de Saint-Jérôme site
- CSSS Champlain—Charles-Le Moyne, Hôpital Charles-Le Moyne site
- CSSS Pierre-Boucher, Hôpital Pierre-Boucher site
- CHUM, Hôpital Saint-Luc site

##### **Quebec City and other areas**

- CHU de Québec, Hôtel-Dieu de Québec site
- Maison Michel-Sarrazin
- CSSS de la région de Thetford, Hôpital de Thetford Mines site
- CHUS, Hôpital Fleurimont and Hôtel-Dieu de Sherbrooke sites

■ **Category 2 centres (20 centres)**

**Planned activities**

- Monthly calls to medical staff (day, evening and night)
- Training days – Customized or based on identified needs

**List of Category 2 establishments**

**Montreal and other areas**

- CSSS Richelieu-Yamaska, Hôpital Honoré-Mercier site
- CSSS Pierre-De Saurel, Hôtel-Dieu de Sorel site
- MUHC, Montreal General Hospital site
- CSSS Jardins-Roussillon, Hôpital Anna-Laberge site
- CHU Sainte-Justine
- Montreal Heart Institute
- CSSS Haut-Richelieu-Rouville, Hôpital du Haut-Richelieu site
- MUHC, Royal Victoria Hospital site
- CHUM, Hôtel-Dieu de Montréal site
- Jewish General Hospital
- Maison de soins palliatifs (Saint-Jean-sur-Richelieu)
- MUHC, Montreal Neurological Hospital site
- CSSS du Sud-Ouest-Verdun, Hôpital de Verdun site

**Quebec City and other areas**

- CSSS de Québec-Nord, Hôpital Sainte-Anne-de-Beaupré site
- CSSS de Chicoutimi, Hôpital de Chicoutimi site
- CSSS de Jonquière, Hôpital de Jonquière site
- CSSS de Rimouski-Neigette, Hôpital régional de Rimouski site
- CSSS de Lac-Saint-Jean-Est, Hôpital d’Alma site
- CSSS du Nord de Lanaudière, Hôpital de Joliette site
- CSSS du Suroît, Hôpital du Suroît site

■ **Other suggested methods**

- To ensure referral of all tissue donors in the establishment
  - Distribution of Tissue Donation posters to all care units (nursing station, family rooms)
  - Standardization of post-mortem documentation
  - Awareness activities for department head and medical staff
- To promote collaborative methods
  - Designation of a resource person at Héma-Québec to follow up with the person in charge of organ and tissue donation
  - Personalized follow-up with the medical staff in the event of a referral and afterward if necessary
  - Recognition of medical staff through ad hoc activities
- To promote outcome measurement and ensure continuous quality improvement
  - Maintenance of a departmental statistics registry
  - Maintenance of a hospital statistics registry
  - Development of performance indicators
- To support and assist the clinical and administrative teams handling organ and tissue donations in establishments
  - Héma-Québec training
  - Distribution of documentation
  - Visits to patient care units

## SUPPORT

A coordinator is available 24/7 on the organ and tissue donor referral line at 1-888-366-7338, option 2.

## TRAINING

Héma-Québec representatives make themselves available to explain the process for identifying and referring potential tissue donors. Training is completely free and equips professionals for this aspect of their work.

For more information  
 Héma-Québec Procurement Manager  
 Telephone: 418-780-4362, ext. 2271

## DOCUMENTATION AVAILABLE TO HEALTH PROFESSIONALS AND ESTABLISHMENTS

Héma-Québec provides Quebec establishments with specially designed tools that simplify and facilitate identification and referral.

## Héma-Québec website

Visit the Human Tissues section of the Héma-Québec website: [www.hema-quebec.qc.ca](http://www.hema-quebec.qc.ca)

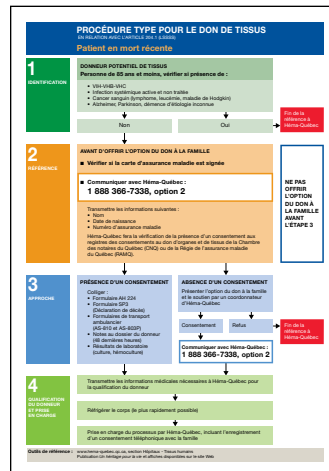
## Standardized Tissue Donation Procedure

This publication is available on the Héma-Québec website



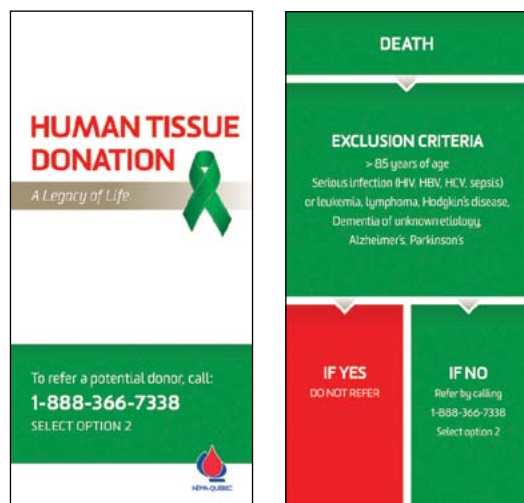
## Standardized tissue donation procedure flow chart

This publication is available on the Héma-Québec website



### Quick reference card

Medical staff receive a quick reference card listing tissue donor eligibility criteria.



### A Legacy of Life guide

When a person dies without making known his or her desire to donate organs or tissues, the decision falls to the family. *A Legacy of Life* is intended for those families. It helps them consider the request and make an informed decision.

This publication is available on the Héma-Québec website.



### Posters

A series of posters with short personal accounts from a medical professional, a donor's family and a recipient's family stresses the importance of tissue donation in hospital settings.



## PERFORMANCE INDICATORS

To track tissue donation in establishments, the Standardized Tissue Donation Procedure has three performance indicators.

<b>1 – Identification</b> (Étape 1 de la procédure type)		
Nombre de donneurs potentiels identifiés :	_____	= Taux d'identification _____ %
Nombre de donneurs potentiels total :	_____	
		Objectif visé 100%
<b>2 – Références</b> (Étape 2 de la procédure type)		
Nombre de donneurs potentiels référés:	_____	= Taux de référence _____ %
Nombre de donneurs potentiels identifiés :	_____	
		Objectif visé 100%
<b>3 – Communication avec la famille et consentement</b> (Étapes 3 et 4 de la procédure type)		
Nombre de consentements au don :	_____	= Taux de consentement _____ %
Nombre de familles approchées :	_____	
		Objectif visé 80%



# PREREQUISITES FOR SUCCESS

There are several prerequisites to improved organ and tissue donation performance and outcomes:

- A formal commitment by the board of directors, general management, and the Council of Physicians, Dentists, and Pharmacists in general and specialized care establishments with a real culture of organ and tissue donation to promoting donation for the benefit of patients on waiting lists and of the community as a whole
- Strong leadership from the whole management team, actively supported by the general director and the director of professional services, with the participation of medical teams and critical care unit managers, as well as a duly mandated donation committee that is actively supported by the establishment
- Sufficient organ and tissue donation training for physicians and clinical staff, with priority given to nurses and respiratory therapists working in critical care—first when they are hired, during departmental onboarding, and then through continuing professional development and skills maintenance
- A commitment to introducing best practices for organ and tissue donation, as well as optimal organization of services, including regular, ongoing analysis of the establishment's outcomes and performance
- Recognition of the interdependencies between identification, procurement, and transplantation centres and establishment of the mechanisms needed to ensure coordination of donor services at every stage of the process at the local, regional, and interregional levels
- Communications activities, including awareness training and educational initiatives directed at institutional managers, physicians, and staff, as well as the community and the general public
- Close cooperation with Transplant Québec and Héma-Québec to carry out organ or tissue donations for transplants or grafts
- Pooling of expertise and support for research

# CONCLUSION

This organizational framework for organ donation and tissue donation services constitutes a serious effort to guide establishments to better structure donation activities and improve outcomes locally and inter-dependently with other establishments. Improving the performance of individual establishments and the entire network will require a firm commitment from boards of directors and management to developing a genuine donation culture. Care will be needed and sufficient resources will have to be provided in order to organize organ and tissue donation activities in line with each establishment's responsibilities. The establishment will need to take local specificities that apply to organ and tissue donation into account.

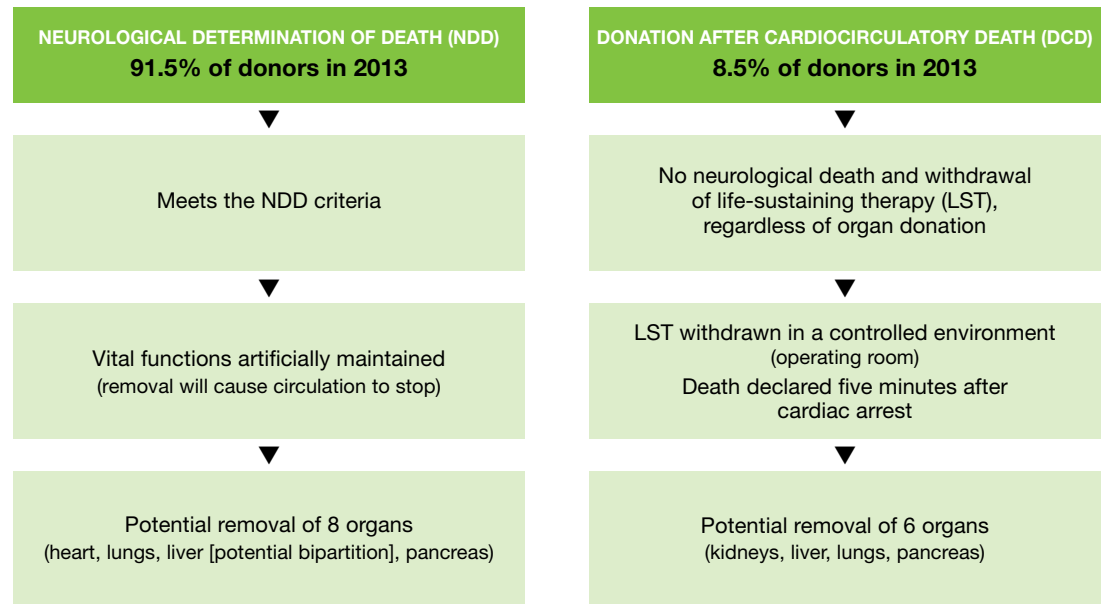
Ongoing effort dedicated to training, improvement of practices, ongoing results assessment, clear coordination, and continued team engagement will be required to improve performance and help establishments meet accreditation requirements. Close cooperation with Transplant Québec and Héma-Québec will also be a key to success. In doing this, establishments will again show their commitment to serving their communities and fulfilling a responsibility to the public.

Collectively, we will better address the needs of waiting patients while honouring the wishes of millions of Quebecers who have agreed to donation after their deaths. These efforts will save lives and improve the quality of life of thousands of people. By actively taking on this social responsibility, general and specialized care establishments will help to save the lives of people waiting for hearts, lungs, and livers. They will also make skin grafts possible for people with severe burns and eye tissue grafts to restore people's sight. And they will enable many to stop dialysis treatment, generating substantial savings locally and for the system as a whole. The benefits for individuals, families, and society as a whole will be numerous.

# APPENDIXES

## APPENDIX 1

### DISTINCTION BETWEEN NDD AND DCD



Source: Transplant Québec

For more information about definitions, identification and eligibility, visit the Transplant Québec website: [transplantquebec.ca/en/identification-and-eligibility](https://transplantquebec.ca/en/identification-and-eligibility)

## APPENDIX 2

### ORGAN PROCUREMENT CENTRES AND ORGAN TRANSPLANTATION CENTRES

#### Organ procurement centres

In Quebec, nine health and social services establishments at 12 sites are designated as procurement centres:

- Centre hospitalier de l'Université de Montréal (CHUM) – Hôpital Notre-Dame and Hôpital Saint-Luc
- McGill University Health Centre (MUHC) – Royal Victoria Hospital, Montreal Children's Hospital and Montreal General Hospital
- CHU Sainte-Justine
- Hôpital Maisonneuve-Rosemont
- Hôpital du Sacré-Cœur de Montréal
- Centre hospitalier universitaire de Sherbrooke (CHUS)
- CHU de Québec
- CSSS de Chicoutimi
- CSSS Les Eskers de l'Abitibi

Removal can also occur in other general and specialized care establishments where a potential organ donor has been identified, particularly after cardiocirculatory death.

#### Organ transplantation centres and programs

In Quebec, eight establishments offer organ transplantation programs at 10 sites

- Centre hospitalier de l'Université de Montréal (CHUM) – Hôpital Notre-Dame
  - Lung transplants
  - Heart-lung transplants
  - Kidney transplants (including living donors)
  - Pancreas transplants
- Centre hospitalier de l'Université de Montréal (CHUM) – Hôpital Saint-Luc
  - Liver transplants (including living donors)
- McGill University Health Centre (MUHC) – Royal Victoria Hospital
  - Heart transplants
  - Heart-lung transplants
  - Liver transplants
  - Pancreas transplants
  - Kidney transplants (including living donors)

- McGill University Health Centre (MUHC) – Montreal Children's Hospital
  - Heart transplants
  - Kidney transplants (including living donors)
- Hôpital Maisonneuve-Rosemont
  - Kidney transplants (including living donors)
- CHU Sainte-Justine
  - Heart transplants
  - Liver transplants (including living donors)
  - Kidney transplants (including living donors)
- Montreal Heart Institute
  - Heart transplants
- Centre hospitalier universitaire de Sherbrooke (CHUS) – Hôpital Fleurimont
  - Kidney transplants (including living donors)
- CHU de Québec – Hôtel-Dieu de Québec
  - Kidney transplants (including living donors)
- Institut universitaire de cardiologie et de pneumologie de Québec
  - Heart transplants

#### Establishments offering living donor programs

- CHU de Québec – Hôtel-Dieu de Québec (kidney)
- CHUS (kidney)
- MUHC – Royal Victoria Hospital (kidney)
- Hôpital Maisonneuve-Rosemont (kidney)
- CHUM – Hôpital Notre-Dame (kidney)
- CHUM – Hôpital Saint-Luc (liver)

#### Pediatric establishments offering living donor programs

- CHU Sainte-Justine (kidney)
- MUHC – Montreal Children's Hospital (kidney)

## APPENDIX 3

### ORGAN DONATION PROGRESS REPORT – ADDITIONAL INFORMATION

#### Facts about organ donors

- Potential organ donors are a rare breed, accounting for only about 1.4% of patients who die in hospital.
- A deceased potential donor who is not identified can result in the deaths of several people.
- A deceased person can donate his or her heart, liver, lungs, kidneys, pancreas, and intestines.
- The cause of death for organ donors is associated with
  - A cerebrovascular accident (CVA) (50%)
  - Head trauma (25%)
  - Cerebral anoxia or other cause (25%)
- Organ donors come from all walks of life and all cultures. Each donor is assessed at the time of donation, regardless of sex, sexual orientation, ethnic origin, or religion.
- Organ donors are found throughout the province and at all establishments, ranging from one to several donors per year.

- In Quebec, the **oldest** deceased organ donor was **88** years old and the youngest, barely 48 hours old. A **76**-year-old donor saved five lives.
- The average donor in 2012 was 50.1 years old. In 10 years, the average donor age has increased by six years from 44 to just over 50.
- Organ donation often gives donors' families a certain sense of comfort and gives meaning to the work of medical staff.
- A living organ donor can give one kidney, a lobe from the liver, and occasionally a lobe from a lung.

#### Patients on the waiting list and transplant recipients in Quebec, by region

The table below shows the 2013 statistics for all organs and just kidneys, expressed in absolute numbers of people and in percentages of the Quebec population.

#### Patients on the waiting list and transplant recipients in Quebec, by region, 2013

ADMINISTRATIVE REGION	POPULATION BY REGION*	% OF QUEBEC POPULATION	TOTAL (ALL ORGANS)				KIDNEY			
			PATIENTS ON WAITING LIST (N=1,047)		TRANSPLANT RECIPIENTS (N=503)		PATIENTS ON WAITING LIST (N=782)		TRANSPLANT RECIPIENTS (N=265)	
01 Bas-Saint-Laurent	199,834	2%	23	2.2%	7	1.4%	18	2.3%	5	1.9%
02 Saguenay–Lac-Saint-Jean	273,009	3%	26	2.5%	18	3.6%	15	1.9%	7	2.6%
03 Capitale Nationale	707,984	9%	76	7.3%	36	7.2%	45	5.8%	14	5.3%
04-17 Mauricie–Centre-du-Québec**	498,274	6%	38	3.6%	19	3.8%	33	4.2%	6	2.3%
05 Estrie	315,487	4%	37	3.5%	14	2.8%	29	3.7%	11	4.2%
06 Montréal	1,981,672	25%	360	34.4%	162	32.2%	284	36.3%	95	35.8%
07 Outaouais	372,329	5%	39	3.7%	21	4.2%	24	3.1%	12	4.5%
08 Abitibi -Témiscamingue	146,753	2%	14	1.3%	9	1.8%	14	1.8%	5	1.9%
09 Côte-Nord	95,647	1%	13	1.2%	2	0.4%	9	1.2%	1	0.4%
10 Nord-du-Québec	42,993	1%	9	0.9%	3	0.6%	7	0.9%	1	0.4%
11 Gaspésie–Îles-de la Madeleine	92,536	1%	10	1.0%	5	1.0%	8	1.0%	1	0.4%
12 Chaudière-Appalaches	408,188	5%	30	2.9%	12	2.4%	23	2.9%	10	3.8%
13 Laval	409,718	5%	57	5.4%	27	5.4%	47	6.0%	10	3.8%
14 Lanaudière	476,941	6%	39	3.7%	21	4.2%	32	4.1%	10	3.8%
15 Laurentides	563,139	7%	63	6.0%	23	4.6%	47	6.0%	14	5.3%
16 Montérégie	1,470,252	18%	175	16.7%	100	19.9%	125	16.0%	53	20.0%
Outside Quebec or information not sent by hospital for the region			38	3.6%	24	4.8%	22	2.8%	10	3.8%
<b>Total</b>	<b>8,054,756</b>	<b>100%</b>	<b>1,047</b>	<b>100%</b>	<b>503</b>	<b>100%</b>	<b>782</b>	<b>100%</b>	<b>265***</b>	<b>100%</b>

\*Source: Statistics Canada, adapted by Institut de la statistique du Québec, February 6, 2013.

\*\*Centre-du-Québec is region 17, but the data have been combined with region 04.

\*\*\*Kidney and double kidney transplant.

## APPENDIX 4

### TRANSPLANT QUÉBEC SUPPORT FOR ESTABLISHMENTS – ADDITIONAL INFORMATION

#### Transplant Québec advisory committees

The **medical scientific advisory committee** consists of 11 physicians from each hospital centre, university institute, or university-affiliated hospital centre performing transplants or involved in transplantation, and university-affiliated hospital centre involved in organ donation, as well as the medical director of Transplant Québec. The committee is tasked with reviewing and standardizing medical and scientific standards and recommending to the board of directors policies and procedures for identifying and managing donors, and organ removal and allocation.

This committee is assisted by three subcommittees (chest, liver, and kidney-pancreas) made up of representatives from each transplant program and one representative for Quebec's histocompatibility laboratories. The primary role of these subcommittees is to propose state-of-the-art allocation procedures that take scientific and medical data into consideration.

The **ethics committee** has eight members. Its purpose is to promote ethical reflection within the organization on the ethical issues raised by organ donation and by the policies and procedures associated with organ allocation. The committee regularly provides advice to the board of directors, to which it reports.

#### Communications and public relations

Activities are organized throughout the year, including

- Comparison of statistics for the calendar year with those of the previous year (mid-February)
- National Organ and Tissue Donation Week (last full week in April)
- World Organ Donation and Transplantation Day (mid-October)

Additionally Transplant Québec regularly publishes the liaison newsletter *Au cœur du don* to inform concerned parties and partners of initiatives in establishments and communities, as well as training activities and the availability of new tools. The newsletter can be downloaded from the Transplant Québec website [transplantquebec.ca/en/publications](http://transplantquebec.ca/en/publications).

The website provides a wealth of information, including statistics. It is a reference source for the public and media, as well as professionals.

The organization's annual report is also a valuable source of information on donation in Quebec, year by year. Annual reports for recent years can be viewed at [transplantquebec.ca/en/annual-reports](http://transplantquebec.ca/en/annual-reports).

For more information, contact Transplant Québec's communications and public relations Department.

### FINANCIAL SUPPORT – USEFUL DEFINITIONS

The following fixed sums are paid to establishments:

- Identification centres
  - \$1,000 for each organ donor accepted by Transplant Québec (since May 17, 2013; previously \$500)
- Procurement centres
  - \$7,000 for each organ donor accepted and used (since May 17, 2013; previously \$4,500)
  - \$1,000 for each organ donor accepted, retrieved from and invalidated

Transplant Québec pays these sums to each establishment annually in the summer following the fiscal year.

- *Identification centre* – Establishment (hospital) that recommended an organ donor who was accepted by Transplant Québec
- *Procurement centre* – Establishment (hospital) where all steps leading up to and including organ procurement take place
- *Accepted organ donor* – Deceased donor who, after an assessment by a Transplant Québec clinical coordinator/advisor, meets the medicolegal and logistical criteria for organ donation
- *Accepted and used donor* – Deceased donor from whom at least one organ has been transplanted
- *Accepted but not used donor* – Deceased donor for whom the assessment and organ donation process was initiated but who, for medical or other reasons, could not continue to the organ procurement stage
- *Accepted, retrieved from an invalidated donor* – Deceased donor who is invalidated in the operating room and from whom no organs were removed or transplanted

For more information, refer to Transplant Québec's identification and payment policy for organ donation from deceased donors.



