

# **A Comprehensive Approach to Organ Donation in Ontario**

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At any point in time, there are more than 1,600 patients waiting for an organ in Ontario.<sup>1</sup> Despite the overwhelming need for organ tissues, Canada has one of the lowest rates of organ donation in the world, at 14 donors per million people (see Table 1 and Figure 1).<sup>2</sup> In comparison, residents of Spain donate organs at rate of 35 donors per million, a statistic that is supported by a highly successful organ donation program that has made great strides in reducing waiting lists through unique policies.<sup>3</sup>

## ***Presumed consent and transplant teams***

How has Spain managed to achieve such a high organ donation rate? There are two main reasons: first, a policy of presumed consent has helped shift attitudes on organ donation, changing donation from an *option* to the *default choice*. Second, financial and logistical resources dedicated to “transplant support teams” provide emotional support to bereaving families, helping decrease refusal rates.

Presumed consent may be described as “opt-out” organ donation, where everyone is assumed to be a potential donor unless noted otherwise. In Canada, all provinces have an “opt-in” approach, where prospective donors must be consulted, relatives must give consent, or the donor must sign an organ donation card before organs may be harvested (Figure 2).<sup>4</sup> However, “opt-in” organ donation is not entirely effective because many people forget to sign their donor cards, are too afraid to sign, or fear that they will not receive the same level of medical care if they are registered as an organ donor.<sup>5</sup> Presumed consent is a solution to this problem. There are two implementations of presumed consent: a “soft” system such as the one Spain uses, where relatives may opt-out for a dying patient, or a “hard” system where relatives may not opt-out for a dying patient. Since 1990 when “soft” presumed consent was implemented by Spain, donation rates have doubled to their current level of 35 per million. Austria’s “hard” presumed consent law was passed in 1982, and since then, their donation rate has quadrupled to 25 donors per million, nearly wiping out that country’s long waiting list for kidneys.<sup>6,7</sup>

As impressive as presumed consent appears, simply amending organ donation laws will not solve Canada’s shortage of organs. Passing legislation is only a small part of a greater shift in attitude that must occur before organ donation rates can increase. For example, Austria is a country of 8 million in which only 8,000 people have opted-out of organ donation – a remarkably small number.<sup>8</sup> Public awareness among health professionals, patients and families about issues surrounding organ donation must increase and needs to accompany any changes to organ donation laws if we are to succeed in improving Canada’s dismal donor rate.<sup>9</sup>

Spain provides an incredible example of the emphasis placed on organ donation awareness. The Spanish government provides special training and funding to transplant teams, headed by a transplant coordinator, whose purpose is to work with relatives and suggest organ donation to grieving families. If a patient is identified as a potential donor, the transplant coordinator and accompanying team are contacted, who immediately meet with relatives, explain the situation, and kindly suggest organ donation.<sup>10</sup> Like any other hospital department, the teams have a dedicated budget and are fully accountable for their performance.<sup>11</sup> It is these teams that have made Spain a world leader in organ donation. Without such a system of education and counselling for bereaving families, a presumed consent law will fail to live up to its potential.

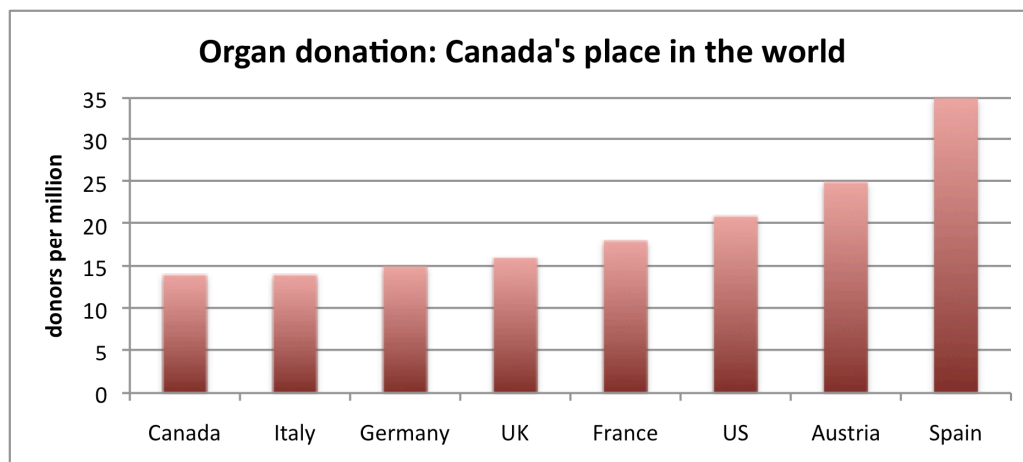


Figure 1. Organ donation rates: Canada's place in the world

Table 1. Organ donation rates by the numbers

Country	Donors per million
Austria <sup>6,7</sup>	25
<b>Canada<sup>2</sup></b>	<b>14</b>
France <sup>12</sup>	18
Germany <sup>13</sup>	15
Italy <sup>14</sup>	14
Spain <sup>3</sup>	35
United Kingdom <sup>15</sup>	16
United States <sup>16</sup>	21

### *Presumed consent in Ontario*

The debate on presumed consent is not new to Ontario, and there has been past discussion of changing to an opt-out system of organ donation. In February 2006, NDP MPP Peter Kormos tabled Bill 61 in the Ontario Legislature, which would implement presumed consent organ donation. At the same time, Progressive Conservative MPP Frank Klees presented Bill 67, which would require all drivers in the province to declare whether they would be willing to donate their organs when they renewed their license. Although the health minister at the time, George Smitherman, seemed to indicate government support for Bill 67, both private members' bills died on the Order Paper in the last provincial election.<sup>17</sup>

In November 2006, the Ontario government commissioned the Citizens' Panel on Increasing Organ Donations, which held public consultations across the province about strategies to increase the supply of organs in the province.<sup>18</sup> The panel's report, released in April 2007, noted that Ontarians did not support presumed consent organ donation. Since the report, there has been no legislative movement with regards to presumed consent. The government did act on some of the other recommendations of the panel, including financial support for living organ donors and non-specific promises about increasing public awareness of organ donation.<sup>19</sup>

### *The future*

Much remains to be done in Ontario before presumed consent can be implemented. Both physician attitudes and public attitudes need to change through increased awareness and

education. Many health care professionals find it difficult to approach dying patients and their families regarding this sensitive topic.<sup>20</sup> However, physicians in Canada need to take responsibility in recruiting donors; there have been reports of donation rates doubling in a hospital simply because a new physician who was dedicated to increasing organ donation had joined the intensive care unit.<sup>8</sup> The government must also provide stable, dedicated financial support to transplant teams modelled after Spain's highly successful system. These teams are essential in building rapport and trust between the medical care team and a patient's family, and provide a service that busy ICU physicians and nurses may not have time for.

Public understanding of the issues surrounding organ donation is essential in building a system that engenders confidence and pride, and not suspicion and doubt. There is much confusion about the meaning of "presumed consent". Will relatives be able to opt-out? Will there be a central registry of non-donors? The debate around presumed consent has often been tainted with impulsive responses such as "organ-seizing ghouls" or "hands off my body". Alarmingly, some citizens are concerned that they may receive poorer medical care as a prospective organ donor. These myths and falsehoods must be addressed, so that proper and meaningful dialogue can take place between the public, health care professionals, and our elected representatives.

Finally, there remain the logistical problems surrounding the implementation of presumed consent. Canada's multicultural mosaic presents a unique problem in distributing information to residents and citizens. A wide range of religious, social and cultural beliefs must be addressed in the public awareness campaign that would accompany a change to the organ donation law. There will no doubt be groups who will be vehemently opposed to presumed consent, and it is the responsibility of the government and the health care establishment to maintain focus on the facts, and not alarmist rhetoric.

Throughout all the debates, consultations, discussions and town hall meetings, we must keep in mind that more than a hundred Canadians die every year while waiting for an organ to become available.<sup>2</sup> In comparison, there have been only nine deaths per year between 2001-2005 attributable to West Nile Virus,<sup>21</sup> an infectious disease that has received disproportionate public and media attention. The urgency of waiting lists is real, and the government needs to take charge with organ donation: increase public awareness, provide strong financial support to organ donation teams, implement presumed consent, and evaluate the program so that all Ontarians will sleep soundly in knowing that should they ever need an organ, the system will be there for them.

#### **GIFT OF LIFE DONOR CARD**

*Please keep this card with your personal identification.*

In the event of my death, I consent to donate the following in the hope that I may help others:

- any needed organs or tissue
  - only the following organs and/or tissue (specify):
- 

\_\_\_\_\_  
DONOR'S NAME

\_\_\_\_\_  
DONOR'S SIGNATURE

\_\_\_\_\_  
DATE

\_\_\_\_\_  
WITNESS' SIGNATURE

**1-800-263-2833**

**[www.giftoflife.on.ca](http://www.giftoflife.on.ca)**



Figure 2. Organ donor card.

## Becoming a donor

Until presumed consent is implemented, prospective donors should sign an organ donor card from the Ontario Trillium Gift of Life Network. Keep this card on your person at all times.

Donors may also register with the Ontario Ministry of Health and Long-Term Care and request to be added to a registry of donors. You will receive a new health card in the mail with your intentions marked on the card.

Remember to speak with your family and loved ones about your choice so that they are aware of your decision and can carry out your wishes in the future.

## Links

Trillium Gift of Life Network: [www.giftoflife.on.ca](http://www.giftoflife.on.ca), 1-800-263-2833

Trillium Gift of Life donor card: [www.giftoflife.on.ca/assets/pdfs/donorCardEnglish.pdf](http://www.giftoflife.on.ca/assets/pdfs/donorCardEnglish.pdf)

MOHLTC registration form: [www.health.gov.on.ca/english/public/pub/ohip/organdonor.html](http://www.health.gov.on.ca/english/public/pub/ohip/organdonor.html)

## References

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