



Education at the Heart of Organ and Tissue Donation

Brief presented to the Committee on Health and Social Services as an order of initiative aimed at studying ways of facilitating organ and tissue donation, in particular the implementation of a presumption of consent

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"Education is the most powerful tool which you can use to change the world."

— Nelson Mandela

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INTRODUCTION

Chain of Life has been a recognized charity since 2014. Its primary mission is to educate teens aged 15 to 17 about organ and tissue donation through the in-school *Chain of Life Program* in order to help save more lives.

Chain of Life firmly believes in young people as agents of change. In teaching them about organ and tissue donation, the *Chain of Life Program* empowers them to make an informed personal decision about this crucial issue, a decision they are invited to share with their families. Young people thus become ambassadors for family discussions about this subject, which then extends beyond the classroom. In this way, the public at large would be reached by the teaching of the program. For Chain of Life, education is the key.

Currently taught in some one hundred public and private secondary schools in almost every region of Québec, the program has impacted over 125,000 young people.

In this brief, Chain of Life will demonstrate the importance, indeed the obligation, of educating the general public in order to dispel certain myths associated with organ and tissue donation and presumed consent. First, we shall demystify the myths regarding presumed consent.



1. MYTHS ASSOCIATED WITH PRESUMED CONSENT

Organ donation is tainted with myths and misconceptions that can skew an analysis, lead to inaccurate conclusions and, in some cases, even bad decisions.

1.1 First Myth – “Everyone in Québec is in favour of organ and tissue donation after death.”

1.1.1 The General Public’s Stand on Organ and Tissue Donation

On the surface, the following assertion in the latest web survey, commissioned by Transplant Québec and published in 2019, would seem to confirm this myth:

“Nine out of ten Quebecers (92%) are in favour of organ donation” (Transplant Québec, 2019, p. 1). This statement clearly reflects Quebecers' values of generosity and altruism, but it does not necessarily reflect their personal wishes regarding organ donation.

In fact, the survey, which is just over five years old, goes on to reveal that 54% of Quebecers have actually posed a concrete gesture, like registering on the *Registre des consentements au don d'organes et tissus* or by affixing a signed sticker on the back of their Health Insurance Card and are therefore, considered willing to donate their organs. Of these, two-thirds have spoken about it with their loved ones.

“The percentage of the population in favour of, or opposed to, donation has nothing to do with the actual number of donors. **“People may be in favour of donating their organs, but if the system doesn't work, it won't happen. The keyword in the Spanish model is organization,”** stresses Rafael Matesanz, founder of the National Transplant Organization in Spain [Organización Nacional de Trasplantes, (ONT)].

1.1.2 Reasons for Not Being in Favour of Organ and Tissue Donation

a. Fear and Discomfort

Thinking about organ and tissue donation involves thinking about one's own death, a subject that is often taboo and difficult to discuss. Fear of death, or simply difficulty talking about it, are frequent obstacles to organ donation.

b. Lack of Trust in Healthcare Professionals

Some people fear that doctors in intensive care will prioritize organ donation over a patient's life. Others are afraid of medical errors, fearing that people will be wrongly declared dead. It is essential to emphasize that the priority of intensive-care physicians is to save lives and that organ and tissue donation is considered only in cases of brain death, a state that is irreversible.

c. Lack of Understanding of the Criteria

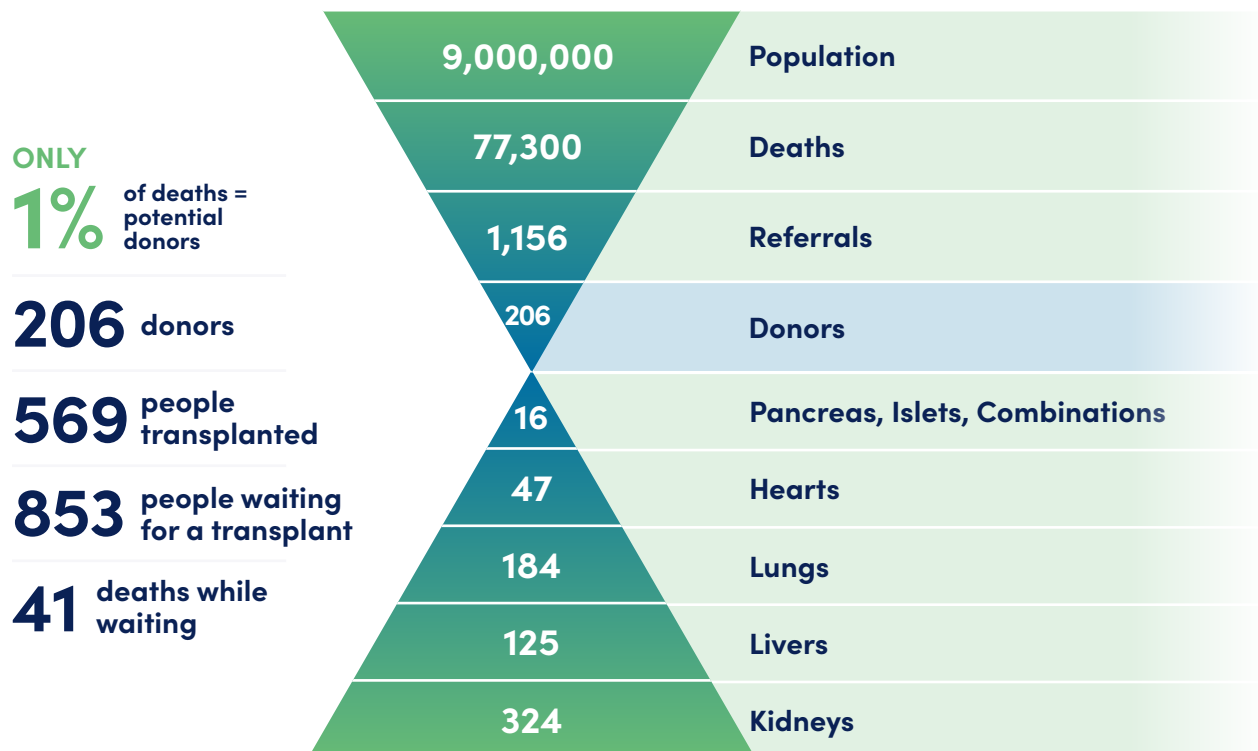
Other reasons cited have to do with prejudice or not knowing the criteria for becoming a potential donor. Some people think they are too old, that they will be turned down because they have been ill or because their religion forbids organ donation. However, there is no age limit to becoming a donor and virtually all religions support organ and tissue donation.

d. Lack of Awareness Regarding the Scarcity of Post-mortem Donors and the Organ Donation Process

The belief that most Quebecers can donate their organs after death is widespread. According to the same 2019 Léger survey, 97% of people are unaware that just over 1% of the population has the potential to become an organ donor. The criteria for becoming a donor are very specific, namely death in hospital due to brain death (encephalic death).

Of the 77,300 deaths in Québec in 2023, only 1,156 were donors referred by Transplant Québec. Unfortunately, 950 of the were excluded during the selection process, and in the end, only 206 donors were able to help save the lives of 569 transplant recipients. These figures underscore the rarity of postmortem donors and the importance of educating and raising awareness about this reality.

Organ Donations and Transplants in Québec in 2023



Source: Transplant Québec and Institut de La statistique du Québec

1.2 Second Myth — “Family refusal is the main cause of organ shortage.”

1.2.1 Reasons for Organ Shortage

While it's true that some families do not agree to donating their loved one's organs, it's crucial to understand that the problem is far more complex than that.

At present, the number of potential donors is already extremely limited, and the same is true in most countries when it comes to brain death in hospital, with a number at around 1%. To this figure we can add potential donors resulting from cardiocirculatory death and people who have requested medical aid in dying. However, the conversion of these potential donors into actual donors warrants particular attention. It takes on average five referenced donors to obtain one actual donor. Each time a potential donor is refused or abandons, several lives are at stake. This is why it's understandable that every refusal or omission is a source of great frustration for the medical donation teams involved, as well as for those waiting for a transplant.

It's tempting to focus primarily on family refusals because they occur when the donor is present physically. They are visible and reversible refusals. However, within the process, they are neither the first factor, nor the most decisive.

a. Unidentified Potential

The process begins with the identification of a potential donor, and the retrospective analysis of hospital deaths reveals that between 5% and 20% of potential donors are not identified in the hospitals monitored. In hospitals without coordinators, this percentage rises to 100% (according to estimates from interviews with donation experts in the field).

The reasons for this are varied, ranging from a lack of training of medical teams to an inability to recognize brain death. This may occur either because the medical teams wrongly assume that the patient does not meet the criteria (due to age or medical conditions), or because they are reluctant to embark in a lengthy process in a context of work overload and a lack of resources, or because of the presumption that bringing up the subject of organ donation would be hurtful to already bereaved families.

For the team that is responsible, identifying a potential donor triggers a complex process which includes information and validation with Transplant Québec, approaching the family, maintaining the donor's condition to ensure that the organs can be retrieved, tests, medical history (including pre-existing illnesses) and the organization of all the protocols required for harvesting the organs.

b. Family Refusals

After validation, the families are approached, but between 20% and 30% will not give their consent (24% in 2022 according to statistics from Transplant Québec).

c. Pre-Existing or Existing Diseases

Pre-existing or current illnesses like cancer, eliminate up to 30% of potential donors.

d. Instability of the Patient's Hemodynamic Status

Throughout the process, the patient's hemodynamic status may become highly unstable, leading to the loss of 10% to 20% of potential donors.

e. Other Reasons for Refusal

Finally, approximately 10% of donors are canceled for reasons such as refusal by the coroner or other factors (according to Transplant Québec's statistics from recent years).

1.2.2 Factors That Influence Family Decisions

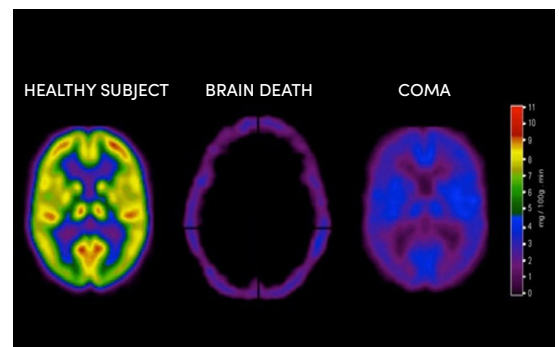
Moreover, in most countries, no matter the legislation and form of consent in place, the ultimate decision regarding organ and tissue donation resides with the family. This decision has to be made within a very short timeframe, usually during one of the most difficult and painful moments, namely the sudden loss of a loved one.

a. Ignorance of Brain Death (Cardiocirculatory Death)

The principal source of organ donors comes from brain death, which is characterized by the complete cessation of all brain activity, and is irreversible. Many people confuse brain death with a coma. Unlike a coma, from which recovery is possible, brain death is indisputably and definitively irreversible. The brain ceases to function before all the other organs, which are maintained artificially. This situation is often disconcerting for donor families who see their loved one kept alive artificially, breathing and having a heartbeat, which complicates their perception of death.

The diagnosis of brain death is based on strict protocol, confirmed by two doctors and comprising several precise examinations. This means that there is no room whatsoever for the possibility of medical error in the diagnostic process. (Photo: Nature Publishing Group)

In this image, a clear distinction can be seen between a healthy brain, neurological death (the total absence of cerebral circulation) and a coma.



Since 2007, in Québec, the potential pool of deceased donors has been expanded to include cases of cardiocirculatory death, which results from controlled cardiac arrest. These are cases where the family has decided to stop life-sustaining treatment, and death has occurred. It is crucial that families understand and accept that their loved one is medically deceased before considering organ donation.

b. Uncertainty of What the Deceased Wanted

Uncertainty about the deceased's wishes is one of the factors that makes the decision extremely difficult for the family. Not having official proof of the deceased's position, or having never discussed the subject together, can complicate the decision-making process enormously, considering that only one out of two people is estimated to have expressed their wish to donate their organs to their family. The rate of family consent in Québec varies between 70% and 80% (74% in 2021).



In the majority of cases, families respect the deceased's choice if it is officially known or if the person had spoken about it. For example, the rate of consent by families in Québec varies between 70% and 80%. For example, in 2021, **only 7% of families refused organ donation against their loved one's wishes** (Transplant Québec statistics, 2021, pp. 1 and 22).

c. Process Length and Delays

The process generally lasts 24 to 48 hours before retrieval, but it can take up to 5 or 6 days. According to Transplant Québec's annual report (Transplant Québec, Statistiques officielles, 2022, p. 26), this long waiting period constitutes one of the main reasons why families refuse to accept transplants. Although there are unavoidable delays associated with tests and analyses, it seems that all too often the waiting period is prolonged because of insufficient resources, unavailable operating rooms and patient relocation. In comparison, Spain manages to complete the process in a much shorter time, about 12 to 18 hours.

Long delays in this process are inhumane for families and should not be tolerated out of respect and dignity for a family in distress.

d. Quality of Support for Families

The quality of the support provided to families plays an essential role in their decision. The role of the coordinators and liaison nurses is to help families make the best decision for them at the most difficult time in their lives.

“A family's consent to a retrieval depends much more on the person making the request than on the person to whom it is made.”

– Rafael Matesanz, ONT founder (in Spain)

The Spanish example illustrates the crucial importance of supporting family members when asking for their consent. While 25% of families are initially reluctant to give their consent, 85% end up doing so thanks to appropriate guidance and support throughout the process provided by specially trained hospital personnel. In short, the quality in the way families are approached has a major impact on consent to organ donation.

Published August 2022, the [SHARE Study](#)) analyzes in-depth interviews conducted with 271 donor families from across Canada. The results clearly demonstrate the importance of providing support to bereaved family and friends, both throughout the donation process and afterwards.

“Improving the organ donation system in Canada requires investment in programs and services in order to create high quality care, centred on the patient and the family.”

In short, efficiency and humanity are the qualities that must guide the entire support team during this process.

It's important to remember that in Québec, we have an end-of-life support process. As such, we must adopt the same approach as in medical aid in dying (MAID) in order to accompany donor families with respect and dignity.

1.3 Third Myth — “Presumed consent improves organ donation.”

1.3.1 Spain's Success with Organ Donation

It is essential to deconstruct the myth that Spain's success in organ donation is based primarily on presumed consent. Although Spain is a world leader in transplantation, it's not because of presumed consent.

In 1979, Spain passed a law on presumed consent, but for the first 10 years following its adoption, there was no real increase in the number of organ donors.

In 1989, all that changed with the creation of the National Transplant Organization (ONT). This organization, dedicated to organ and tissue donation, set up teams of donation professionals with coordinators in every hospital and provided centralized support for the entire process. In its first 25 years, the ONT trained over 18,000 coordinators.

The results have been spectacular, with the number of donors more than doubling in just 10 years, soaring from 14 donors per million population (pmp) to 34.

Contrary to the idea of presumed consent, **Spain has never created a refusal register**. Instead, it has taken a proactive approach by dialoguing with the families of the deceased about the possibility of organ donation, without necessarily referring to the law on presumed consent.

Moreover, since 2013, Spain has increased the number of potential donors through controlled cardio circulatory death, reaching a record of 49 donors per million. Again, this success stems from much more than the law on presumed consent. It is the result of the creation of a solid infrastructure and a proactive approach to organ donation, with the ONT playing a key role.

Two Relevant Articles

“Opt-out legislations: the mysterious viability of the false”

<https://pubmed.ncbi.nlm.nih.gov/31122708/>

Matesanz R, Domínguez-Gil B, Coll E, & al. (2017). “How Spain reached 40 deceased organ donors per million population.”. *Am J Transplant*, 2017. pp. 1447–1454.

<https://www.sciencedirect.com/science/article/pii/S1600613522250060>

1.3.2 Presumed Consent: No Proof of Improvement in Organ Donations

Presumed consent has been adopted in over 25 countries worldwide, the first as early as in the 70s. However, it has not been shown to significantly increase organ donations over the explicit consent model.

Numerous studies have been carried out to compare results between countries with a presumed consent system and those with an explicit consent system. However, none of these studies was able to establish a conclusive positive impact of presumed consent on organ donations. A major study published in 2019 examined data from 35 countries, 18 of which had an explicit consent system and 17 that had a presumed consent system. The average results revealed that, in terms of deceased donors per million population, there was an increase of 4.9 in the countries with presumed consent compared with those with explicit consent (20.3 vs. 15.4). However, in terms of living donors, countries with explicit consent showed a significant increase of 10.9 compared to those with presumed consent (15.7 vs. 4.8). Finally, in terms of the number of transplants per million population, presumed consent fared slightly higher than explicit consent (63.6 vs. 61.7), a difference of only 1.9 transplants per million.

The authors of the study consider that Spain can clearly be likened more to a country that practises explicit consent rather than presumed consent when it comes to organ donation. Instead, they emphasize that raising awareness and educating the population is the best strategy for improving organ donation.

This conclusion is drawn from their study entitled “Comparison of organ donation and transplantation rates between opt-out and opt-in systems,” (Arshad A, Anderson B, Sharif A, 2019, pp. 1453–1460).

1.3.3 Presumed Consent and Public Trust

To assess the effects of a change in the law, it is essential to analyze the results before and after the modification, taking into account the absence of other simultaneous changes.

a. Brazil

A convincing example is Brazil, which adopted presumed consent 20 years ago, but had to backtrack after just one year, due to negative reaction by the people and a loss of trust.

b. Chile

Chile also opted for presumed consent in 2010, resulting in a 27% drop in the number of donors per million and a family refusal rate of over 50% beginning the first year. Ten years later, the number of donors per million was still stagnating below 10.

c. England and Holland

The two most interesting recent cases are England and Holland as they are the only countries that really invested in new computerized registers and massive campaigns to raise public awareness and really explain how the law had changed.

In England, this change took place in May 2020.

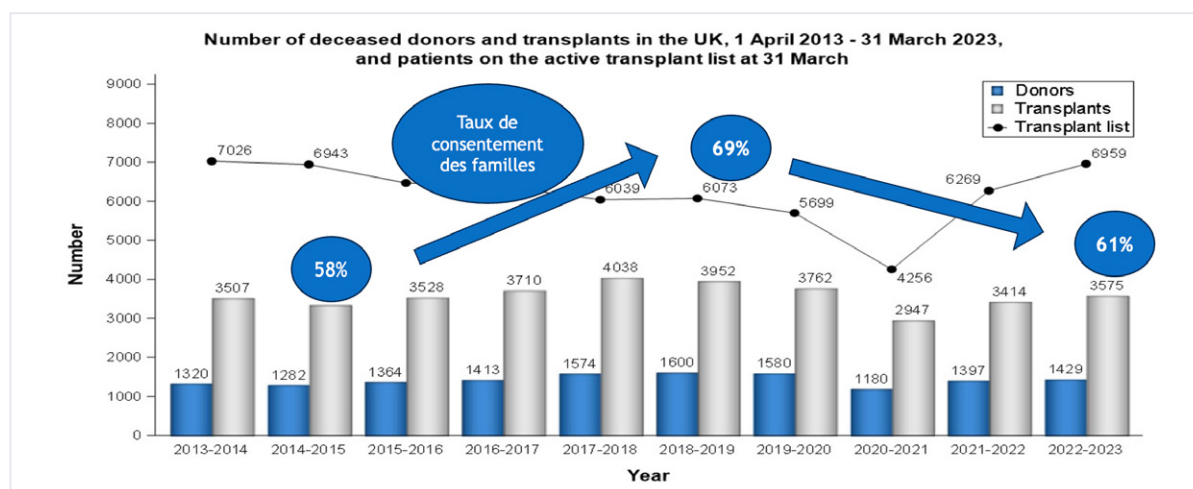
A vast multimedia awareness campaign was conducted over a two-year period to inform the public of the change in the law. Its marketing budget of 11.7 million £ (\$23 million CAD) was the largest sum ever invested in England. Here are four extracts from the National Health Service Blood and Transplant (NHSBT) board meeting (March 28, 2023) which summarize the motivation for the change, its impact and the results:

The opt-out system [presumed consent] was introduced to help save and improve the quality of life of more people by changing the default position in order to facilitate donor recruitment. Eight out of ten people are willing to donate, so the system change was intended to better reflect public opinion. Recent focus group studies indicate that the public believes that the opt-out system would be sufficient for donation to take place since it is assumed that everyone would be automatically registered. Unfortunately, the new legislation is less efficient than hoped for (NHSBT, March 2023).

By the end of 2020, 75% of the people in England claimed they were aware of the change. [...] The consent rate is at the lowest level since 2014–2015 and the active transplant waiting list is at the highest level in almost ten years. [...] The family consent rate rose each year between 2014 and 2019, rising from 58% to 69%. It dropped to 66% in 2022 and now stands at 61%.

In 2018–2019, before the switch to presumed consent, 25.3 million people had registered a consent on the register (including 1 million more that year) and 0.6 million had registered a refusal. By 2022–2023, 28.3 million people had registered a consent decision (including 0.7 million that year, the lowest figure since the register began in 2015), and 2.4 million people, or 4% of the population, had registered a refusal decision (NHSBT, March 2023).

With the consent situation worsening and the waiting list for transplants getting longer, we need to revolutionize our marketing approach to save and improve more lives.¹



Source : Transplant activity in the UK, 2022-2023, NHS Blood and Transplant

In 2020, after several tedious years of debate, the Netherlands also adopted presumed consent by a very narrow margin—winning by just one vote! The register gave citizens three options: accept, refuse, or leave the decision to the next-of-kin. Individuals who didn't register received a mandatory notice at home, followed by a reminder. Consent increased from 3.8 to 4.8 million people, **while refusals nearly doubled, soaring from 2.3 to 4.3 million**. In total, 76% of the Dutch people expressed their choice, but those who had to be incited to do so tended to lean more towards the opposition.

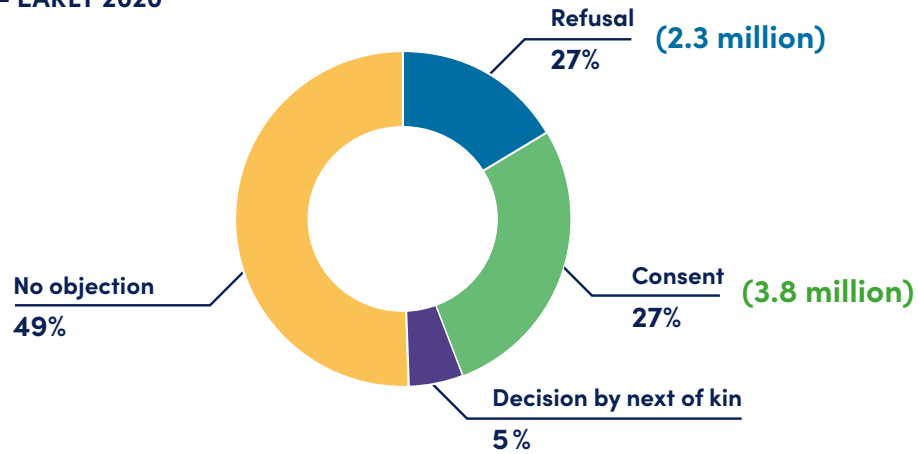
Holland invested 40 million euros in this transition, including 15 million in the media campaign. The results show that the family consent rate, which was initially very low at 48% in 2020, climbed to 55% in 2022, but the number of deceased donors remained stable at 16 donors per million from 2019 to 2022.

1. NHSBT Board Meeting, March 28, 2023, <https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/29370/agenda-item-41a-health-of-the-odr.pdf>

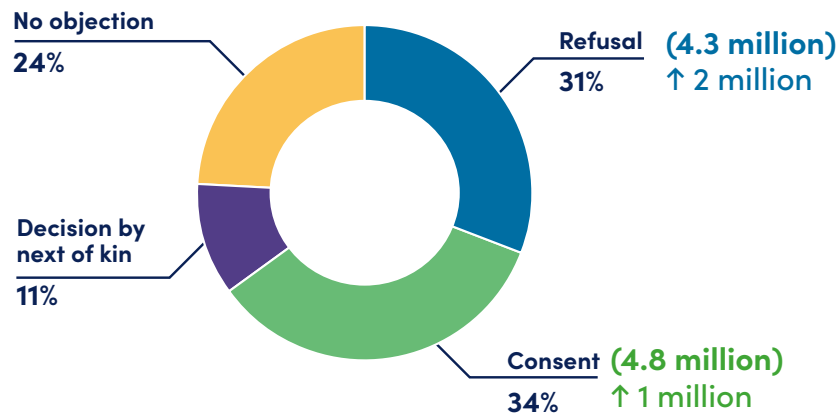
Donor Register Registrations in Holland

Registration of 76% of the population

PHASE 1 — EARLY 2020



PHASE 2 — MID-2021



Source: [Statistics Netherlands](https://www.cbs.nl/en-gb/news/2023/43/10-7-million-adults-have-registered-their-organ-donation-choice?pk_campaign=social_share) 2023/10/26):
https://www.cbs.nl/en-gb/news/2023/43/10-7-million-adults-have-registered-their-organ-donation-choice?pk_campaign=social_share

1.3.4 Presumed consent is not consent.

In organ donation, presumed consent is not consent. The verb “to consent” comes from the Latin and conveys the idea of “to be in agreement.” But how can we presume that someone agrees to something without first asking for their opinion? How is it possible to know that someone agrees to something without knowing what they think? Presumed consent is, in fact, not true consent.

How can we presume that someone agrees without giving them the opportunity to express their opinion?

Imagine taking blood, or even an organ, from a living person without their permission, simply because of a shortage. The only difference with a post-mortem retrieval lies in the fact that the donor is deceased. While alive, the person would have been able to refuse or accept. It is difficult to deduce someone’s presumed consent without an explicit expression of their wishes.

If a person has never heard of organ donation, or feels unconcerned by it, it is incoherent to claim that they are in favour of this law or against it. The concept of consent cannot be linked to mere presumption. It simply makes no sense. What's more, it's hypocritical to claim that anyone can refuse by signing a refusal register, knowing full well that the majority of people will not do this. In England, for example, only 4% of the population had done so after two years.

1.3.5 Presumed consent to organ donation is no longer a donation.

When the state decides that we are all organ donors by default, it completely alters the essence of donation. To “donate” something implies a voluntary act, a personal choice guided by values such as generosity and compassion. Thus, it is no longer a voluntary act of giving, but rather a legal obligation, fundamentally changing the meaning of organ donation.

Ultimately, for donor families, agreeing to organ donation for a loved one means accepting that their loved one's life will be prolonged through others, thus giving meaning to death and helping them through the grieving process.

Organ and tissue donation is rooted in universal values in each and every link of the donation chain. These values, identical to those that unite Quebecers, transcend our hearts and our collective DNA: generosity, solidarity, respect, human dignity, altruism and love for others. These values, which we have been so successful in integrating into the process of medical aid in dying, should guide our reflections on legislation modifying organ and tissue donation.

2. EDUCATION AT THE HEART OF ORGAN AND TISSUE DONATION

2.1 Educating About Organ and Tissue Donation: The *Chain of Life Program*

To raise awareness, to inform and to educate are different approaches for engaging individuals in a given subject. “Educating” involves in-depth preparation of the subject matter in order to achieve a level of understanding and awareness that will enable commitment. Chain of Life's education program has the double objective of developing competency in English as a second language (ESL) and raising young people's awareness about a crucial societal issue: organ and tissue donation. It goes beyond the mere dissemination of knowledge by fostering connections between information in order to achieve deeper understanding and meaningful awareness.

The program aims to ensure that young people not only acquire knowledge but also develop both the competency and attitudes that will transform their perspectives. In order to do this, various activities and learning strategies show them how language skills learned in English class can be applied to making informed decisions about organ and tissue donation. The ultimate goal is to empower young people to civic action, by encouraging them to initiate family discussions on this vital subject.

2.2 The Empowerment of Young People for a Culture of Organ Donation in Québec

Education plays a central and crucial role in promoting organ and tissue donation. It holds extraordinary power, particularly by helping young people become agents of change committed to creating a true culture of organ and tissue donation in Québec.

Formal education enables young people to acquire an in-depth understanding of the issues surrounding organ donation. They acquire the necessary knowledge about how the transplant system works, the pressing needs of patients waiting for organs and the challenges faced by donor families, medical teams and all those involved in the donation chain. This solid knowledge base serves as the foundation of their commitment.

What's more, education has the power to demystify the misconceptions and myths surrounding organ donation. Thus, teens have accurate, factual information on which to base their personal opinions, enabling them to be better prepared to raise the awareness of others and contribute valuable input to family discussions about organ and tissue donation.

Education about this vital issue enables teens to put the values of generosity, empathy and solidarity to work within our society. They learn that organ donation is an altruistic act with the potential of saving lives and bringing hope to those in need. It can also boost their confidence in their ability to act as ambassadors for family discussions about organ donation, as well as allow them to raise awareness in their community by using social media to spread the message. Education provides them with the tools they need to become effective advocates for this crucial cause.

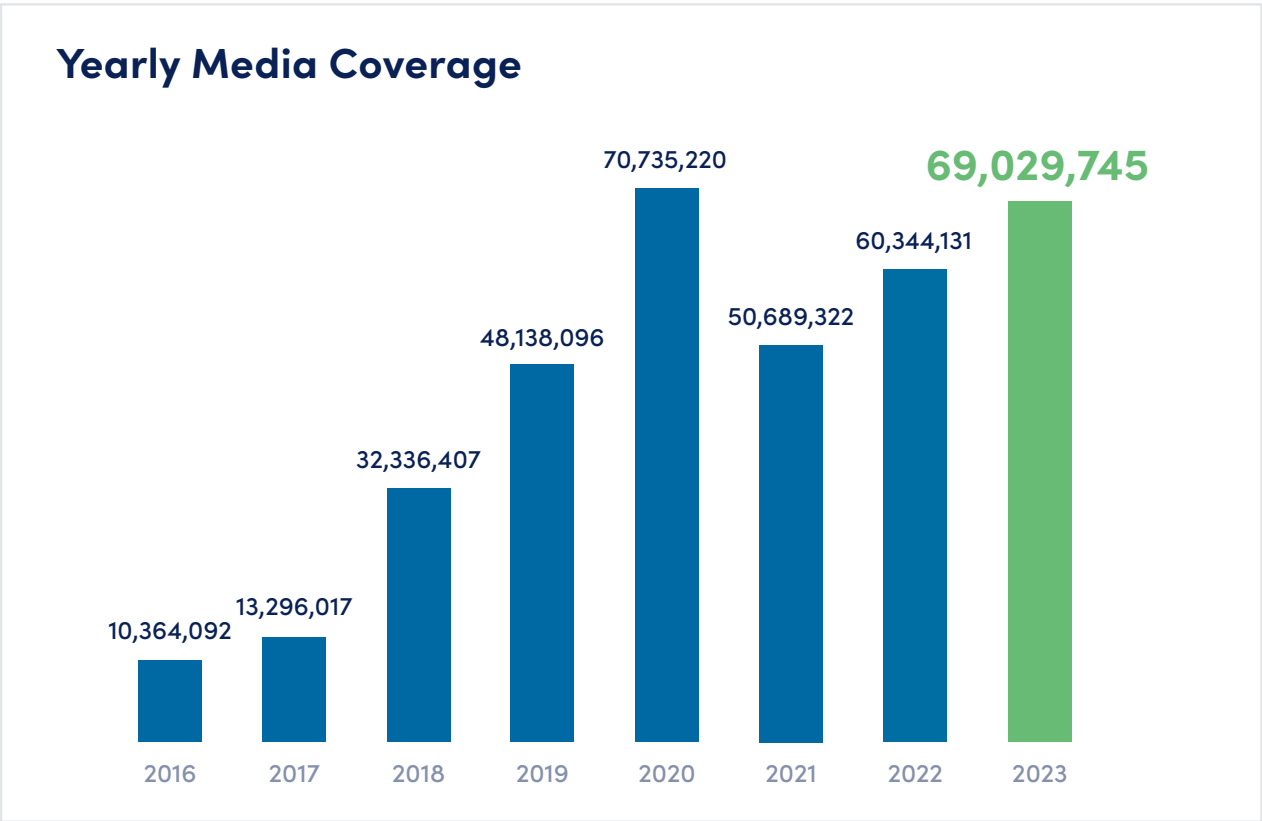
2.3 The Strengths of Chain of Life

There are a number of organ donation programs, but Chain of Life is the only one to have emerged from the school environment.

The program highlights the celebration of life, open and meaningful discussions and, above all, free choice. It is the only one to target **ONE** clientele and **ONE** academic subject. And it's the only one to include a health component. The underlying principle of the program is that the scarcity of organs increases their value; hence, the importance of keeping them healthy.

In addition, Chain of Life has obtained a great deal of recognition and support over the years, (Appendix F), well as exceptional visibility ever since 2015, thanks to the Chain of Life Challenge.

Here is a general overview showing the scope of our media coverage over the years.



Estimated value of visibility obtained in advertising in 2023:

→ **\$662,995** ←
↑ ↑

RECOMMENDATIONS

1. That the in-school *Chain of Life Program* on organ and tissue donation be offered in all secondary schools in Québec.
2. That the education and health communities work closely together to educate about organ and tissue donation.
3. That organ and tissue donation remain a free gift, part of an informed process within a democratic society that respects the free choice of its citizens.
4. In short, that the Québec government make organ and tissue donation education and its entire infrastructure a national priority.

CONCLUSION

Education, especially of our young people, is proving to be a powerful driving force in creating a culture of organ and tissue donation in Québec. As such, according to Chain of Life, the government should be investing in education.

Thanks to Chain of Life's innovative education program and the organization's expertise, Québec could emerge as a world leader in organ and tissue donation education, thereby creating an exemplary model for society. In addition, it could mobilize the Québec population around a more altruistic and healthier culture by leveraging the power of young people as agents of change, thus helping save more lives.

A Great School Project

Here's one example of a project initiated by a student at the Polyvalente de Thetford that has had an impact on the community and which even received a mention at the Québec National Assembly on May 23, 2023.

Read the article on [LeSoleil.com](https://www.lesoleil.com) (in French)



Photo: Le Soleil, Yan Doublet



EDUCATION
AND TISSUE
DONATION:

YOUTH MADE **AWARE**
WELL-INFORMED **FAMILIES**
MORE LIVES SAVED

A HIGHLY RECOGNIZED ORGANIZATION AND ITS INNOVATIVE PROGRAM

Since 2014, whether through conferences (university audiences, professional associations and social groups), television and radio interviews, or articles in the general and specialized press, media coverage of Chain of Life has been increasingly wide-ranging (at regional, national and international levels). On numerous occasions, the organization has been called upon to talk about the *Chain of Life Program*, which is considered innovative and exemplary. What's more, the organization has received an impressive number of distinctions and various forms of support, demonstrating the breadth of its scope and the vitality of its existence. One thing is certain: Both Chain of Life and its education program are spreading their wings virtually everywhere. In short, Chain of Life is paving the way for civic-minded education, the image of a society that takes responsibility through collective social capital, where education is a positive vector.

The History of Chain of Life

The Chain of Life organization has a unique history shaped by the altruism, dedication, determination, perseverance and passion of a highly dynamic team. A woman of heart and founding president, Lucie Dumont created Chain of Life while she was a secondary ESL teacher and education advisor. After a classroom visit and the moving testimonial of a young Ontarian who was travelling across Canada to talk about organ donation, and who was himself awaiting a transplant, Ms. Dumont set up a committee comprised of teachers, students and a staff member at the Centre de services scolaire de Kamouraska—Rivière-du-Loup. Together, in 2007, they designed a first website to raise the awareness of teens about organ and tissue donation. This led to the creation of stimulating educational activities and, in turn, the creation of a unique learning and evaluation situation (LES) on organ and tissue donation. As defined by the government of Québec (2007), an LES is “composed

of a context associated with a problem and a set of complex tasks linked to knowledge [...] which allows students to explore the problem in greater depth (p. 5). The LES produced by Chain of Life gave rise to several rewrites by an experienced team, as well as field testing. At the same time, invaluable partners, including Transplant Québec, came onboard. Their significant contribution made it possible to obtain substantial financial aid from Desjardins to produce the Chain of Life pedagogical kit. Finally, it was in April 2014, after seven years of labour requiring energy, determination, commitment and passion, that the *Chain of Life Program* was officially launched. Subsequently, in 2017, Chain of Life became a registered charity. The altruistic commitment of Chain of Life can be seen as “a new way of expressing citizenship, extending the dynamics of social responsibility” (Conseil d'État, 2018, p. 59).

Why We Exist

By educating teenagers 15 to 17 years of age about organ and tissue donation, Chain of Life provides them with the tools they need to make a free and informed decision regarding this important social issue. As well, this education not only reaches students, but also their families. Families discuss organ and tissue donation at home, expressing their personal opinions and decision regarding their choice. Through the *Chain of Life Program*, young people become ambassadors for family discussions, a civic gesture of capital importance to help reduce the number of refusals from families and increase the number of organ and tissue donors. Hence, the slogan: **“Youth made aware = Well-informed families = More lives saved”!**

The *Chain of Life Program* also reminds us of “the power in combining the worlds of education and health” (Transplant Québec, 2021, p. 5). Teens learn to appreciate the fragility of life and the importance of adopting healthy lifestyle habits for a healthy body. Education is, thus, a place for information, dialogue, reflection and raising awareness about current issues involving everyone's health and indeed, everyone's life.

Vision

That the *Chain of Life Program* be taught in every secondary school in Québec (as well as elsewhere) in order to help save more lives by leveraging the power of young people as agents of change.

A Two-Fold Mission Based on Dialogue

- a) To educate young people aged 15 to 17 about organ and tissue donation and make them ambassadors for family discussions, ultimately, in order to save more lives.
- b) To make young people and the general public aware of the inestimable value of a healthy body and the importance of taking care of it.

More specifically, the *Chain of Life Program* is offered in Québec schools, in Secondary Cycle Two (Secondary IV and V) during ESL or English, mother-tongue classes. In the scope of this evaluation, we are interested in the ESL program delivered by qualified teachers who believe in the values put forth in the program, but also in their didactic and pedagogical capabilities, as well as its educational value. [...] Below are the underlying values of the *Chain of Life Program*, the approach of which is intergenerational.

Altruism

Agreeing to donate one's organs and tissues is a gesture that is completely free and voluntary, a gift that is an expression of compassion and generosity.

Solidarity

The *Chain of Life Program* raises awareness to the fact that a society functions better when everyone contributes to its collective well-being. Students are encouraged to act as good citizens by becoming ambassadors of family discussions about organ and tissue donation, ultimately helping save more lives.

Health

The *Chain of Life Program* helps young people become aware of the inestimable value of a healthy body and the importance of taking care of it. By adopting a healthy lifestyle, we act proactively to help reduce the growing number of chronic diseases.

A Unifying Social Project

In addition to the education provided in schools through its education program, Chain of Life organizes activities to raise public awareness about the essential role of each link in the chain of life. One example of this is the Chain of Life Challenge, held in conjunction with World Organ Donor and Transplant Day, promoted by the World Health Organization, where children and adults climb to the top of mountains across Québec, and elsewhere in the world, carrying with them great hope for those waiting for a transplant. As Canadian Blood Services explains, the Chain of Life Challenge is “a great gathering where everyone in the donation chain comes together to support Chain of Life, a unique education program, [...] thereby creating a movement that brings together all those touched by organ donation.” And so it is that this unifying day for citizens brings together simultaneously, at the foot of some twenty mountains located throughout Québec, in Canada and beyond, the education sector (students, parents and school staff), the healthcare sector (doctors and nurses), the general public (transplant recipients, donor families and and citizens), elite climbers and public figures. Every year, the Québec media pick up on this event, highlighting the solidarity between education, health and citizens who come

together for the cause: “Organ donation education is essential.” That's the message from doctors and citizens across Québec. [...] In October 2023, the Chain of Life Challenge focused on education about organ and tissue donation by honouring donor families, “an opportunity to show families that they are supported and to initiate discussions about organ donation at home.” Thus, taking collective responsibility and acting together is the solution to organ and tissue donation, where Chain of Life not only plays a leading role in educating young people, but also calls on and rallies together the major players in this issue, which takes on the form of a unifying social project.

Collective initiatives, such as walks and climbs by students, teachers and engaged citizens are also organized as a gesture of solidarity for the cause. To these are added other civic gestures, such as that of the two cyclists who, in the summer of 2022, pedaled 5,000 kilometres across Canada to raise funds for Chain of Life, as well as those of people who volunteer their time, talent and dedication. In other words, “so many small gestures that give great results,” a magnificent demonstration of solidarity for the cause and in support of in-school education!



Students and teachers from the Polyvalente de Saint-Jérôme during a Chain of Life climb to the top of Mont Tremblant in the fall of 2023. [Read the article on the Chain of Life blog.](#)

THE CHAIN OF LIFE PROGRAM

Teachers Trained Throughout Québec

The *Chain of Life Program* is offered in some one hundred public and private secondary schools in almost every region of Québec, reaching tens of thousands of young people every year. More specifically, the program is offered in Secondary Cycle Two (Secondary IV and V) during ESL classes. To date, over 350 ESL teachers (including some 20 ESL education advisors) have taken the one-day training session offered by the organization to ensure they are adequately prepared to teach the education program and network with the “great Chain of Life family.” As well, doctors, nurses, transplant recipients and donor families contribute to the education program in a variety of ways, including touching testimonials, educational videos and the validation of scientific information.



An Essential and Highly Appreciated Training Session

The training session, pedagogical toolkit, teaching-learning material and other tools are provided to all participants (free of charge) and correspond to a meaningful and dynamic LES. This LES is closely aligned with the Québec Education Program (QEP) for Cycle Two secondary school (Gouvernement du Québec, 2006). In particular, the *Chain of Life Program* is directly linked to ESL by developing the ESL competencies, which enable students to improve their ability to communicate, both orally and in writing, while at the same time fostering openness to the world. It also aims to integrate and consolidate knowledge, skills and know-how related to two broad areas of learning, namely Health and Well-Being and Citizenship and Community Life. [...] In addition, in August 2023, the new curriculum for secondary

schools, Culture and Citizenship in Québec (CCQ) (Gouvernement du Québec, 2024) was introduced. While its implementation is optional during the 2023–2024 school year, it will be mandatory in all Québec schools during the 2024–2025 school year. At the heart of the program are three goals: “to prepare to exercise citizenship in Québec; to aim for recognition of oneself and of others; and to pursue the common good” (Gouvernement du Québec, 2024, p. 3). Students' participation in the CCQ program (Government of Québec, 2024) enables them “to develop analytical, reflective and relational skills, by engaging in dialogue and critical thinking, so that they will be prepared to fully exercise their role as citizens of Québec at their current stage of life and in the future” (p. 3). More specifically, this program

defines citizenship as the “institutionalization of the connection between individuals and a political community through the granting of rights (civil, political and social) and their associated obligations and responsibilities [...] that foster recognition of oneself and of others as well as the pursuit of the common good” (Gouvernement du Québec, 2024, p. 3). This citizenship is part of a culture that corresponds to “a set of more or less formalized ways of thinking, feeling and acting, which are shared and bring people together as part of specific and distinct collectivities” (Gouvernement du Québec, 2024, p. 5). In short, it is through dialogue and the development of critical thinking that young people are led to develop as citizens within the culture of the Québec community. To this end, LESs that are “meaningful, open and complex” (Gouvernement du Québec, 2024, p. 14) will foster the development of the two following competencies: Competency 1 – Studies cultural realities; Competency 2 – Reflects on ethical questions. It is through dialogue that “students develop their ability to listen, their self-esteem and

their openness to others” (Gouvernement du Québec, 2024, p. 5), while critical thinking is an “evaluative, substantive and self-correcting practice that makes use of a variety of resources to determine what is reasonable to hold to be true or to do” (Gouvernement du Québec, 2024, p. 5). Ultimately, LESs must engender a reflective approach to diverse practices of citizenship “that involve various ways of expressing ideas and points of view. When engaging in dialogue, students are encouraged to be attentive, discerning and respectful of the dignity of others, while critically examining ideas, points of view and reference points. In this way, they work toward taking their place as citizens in Québec society and participating actively and constructively in democratic life” (Gouvernement du Québec, 2024, p. 8). From then on, the practice of citizenship translates into “a citizenship of each day, made of commitment and solidarity, that reconnects with a fundamental dimension of citizenship: exemplary action. Being a citizen means first and foremost committing to the service of the common good in daily life” (Conseil d'État, 2018, p. 14).

A Program That Generates Great Interest

In addition to covering the subject-specific competencies targeted for this level, the LES in the *Chain of Life Program* proposes a variety of effective pedagogical approaches and resources to stimulate interest, motivation and civic engagement among young people through dialogue and the development of critical thinking. Indeed, the LES is meaningful in that it encourages genuine questioning on the part of students, leads them to express themselves and enables them to take charge of their own lives without restrictions, thereby increasing their motivation and commitment (Houssaye, 1993). Furthermore, the activities they engage in foster the development of cross-curricular competencies (e.g.: Uses information, Exercises critical judgment, Cooperates with others and Communicates appropriately). Organ and tissue donation is without doubt a sensitive topic because it touches upon personal values and is the subject of societal debate. Hence, its ability to foster the development of a range of skills in students who “will discuss it among themselves, exchange their different points of view, seek to convince—even influence—each other” (Hirsh, Audet and Turcotte, 2015, p. 6). Thus, the



LES meets the recommendations of the Ministère de l'Éducation regarding the role of teachers who “work to create an atmosphere conducive to dialogue between members of the learning community in the classroom, where each person feels they can express themselves freely” (Gouvernement du Québec, 2023, p. 14). [...] For teachers, the *Chain of Life Program* is a turnkey, captivating program that “joins a framework of schoolbased knowledge and academic outcomes” (Lebrun & al., 2006, p. 353) through its three sections: education, health and social values.

Stimulating Activities and Teaching Tools

First of all, the *Chain of Life Program* consists of the teacher's guide entitled *Teacher's Guide – Celebrating Life Through Organ and Tissue Donation* (Chaîne de vie, 2015). Comprehensive, in color, and featuring images and photos, it includes accurate and relevant information on organ and tissue donation as well as a glossary of specialized terms. Very well organized and easy to use, the approach to be taken is clear, stimulating activities to be carried out with students are presented, while leaving room for the teacher's creativity, as well as assessment ideas, suggestions for differentiated instruction to reach all young people and additional activities. In addition, for each activity, an overview of the tasks is provided, indicating the approximate time required, the competencies targeted and the teaching and learning materials to be used. The variety, quality, and relevance of the materials are worth highlighting, as they directly engage students and undeniably support learning through teaching in a highly motivating educational environment. Below are a few examples that give an idea of the richness of the materials: educational videos made by medical specialists; meaningful testimonials (from teachers and students, as well as transplant recipients and donor families); explanatory texts and touching audio letters; a dynamic PowerPoint presentation and an interactive website; role-playing cards; a USB drive filled with resources. In short, these teaching tools draw on authentic and representative situations so that teens can understand the reality surrounding organ and tissue donation. These tools are also a real support for active teaching, which gives teens the space they need to form an informed opinion. In addition, along with suggested time allocations and procedures, there are suggestions for classroom work modes (individual, pairs, teams, or whole class). There is also a 24-page student workbook with images in black and white to facilitate photocopying. To give you an idea, here are the main topics covered in the education program.

- Organ and tissue donation: facts and myths; organs and tissues that can be transplanted; key players (donors, people awaiting transplants, recipients, transplant specialists, nurses, donor families, etc.); constraints (organ availability and compatibility); the waiting list.
- The importance of making an informed decision about organ and tissue donation and sharing it with loved ones.
- Scientific advances: ex vivo, organogenesis, artificial hearts, stem cells, etc.
- Ethical issues: respect and dignity of the individual; organ allocation; organ commercialization; consent.
- Health: the essential role of organs; the principle of scarcity; the importance of adopting healthy habits.
- The celebration of life.

It is clear that the *Chain of Life Program* supports the development of Competency 1 – Studies cultural realities from the CCQ program (Gouvernement du Québec, 2024) by promoting civic engagement in which students “discover the possible areas of freedom and action as well as the guidelines that provide a framework for collective life in Québec” (p. 16) with regard to organ and tissue donation. It also contributes to the development of Competency 2 – Reflects on ethical questions. (Gouvernement du Québec, 2024) by facilitating through dialogue students’ capacity “to understand a situation from an ethical standpoint and to build on an in-depth examination of concepts, points of view and their foundations to choose reference points and responses that foster the recognition of oneself and of others and the pursuit of the common good as part of the informed exercise of citizenship in Québec” (p. 21) with regard to organ and tissue donation.

In addition, through these two competencies, students in Cycle Two (Secondary IV and V), the target audience for the *Chain of Life Program*, will be encouraged to

address organ and tissue donation through the themes targeted in the CCQ program (Government of Quebec, 2024), such as relationships and kindness, justice and law and the search for meaning and worldviews. In other words, at the heart of the *Chain of Life Program*, teenagers are educated about organ and tissue donation so that they can form an informed opinion on the subject, but also become aware of the inestimable value of a healthy body. First, education about organ and tissue donation is a “golden opportunity” to promote healthy lifestyles among students. In a context where the demand for organs for transplantation far exceeds supply, notably due to the increasing prevalence of chronic diseases, it is essential to address health issues related to unhealthy lifestyles that affect vital organs (heart, lungs, kidneys, liver, etc.). The principle underlying the health

component of Chain of Life is that “the scarcity of organs increases their value,” hence, the importance of keeping them healthy. Second, adolescents become emissaries for exchanges in their families and within our current and future society, promoting a sense of civic engagement. The latter “is a citizenship rooted [...] in sharing with others” (Conseil d’État, 2018, p. 61). From this perspective, educating young people is undoubtedly the best solution as it provides a favourable context for the development of civic values that guarantee the success of organ and tissue donation among the population. In short, Chain of Life and its education program are part of a social project that mobilizes and brings together civic actions, echoing a crucial issue: organ and tissue donation.



Teachers during a Chain of Life training session

EVALUATION OF THE PROGRAM: A FEW CONCLUSIVE RESULTS

1. CONTEXT

In the spring and fall of 2022, a study was conducted by two university researchers, the general objective of which was to portray the role of organ and tissue donation education in secondary schools and the innovative contribution of the *Chain of Life Program* in this respect.

2. METHODOLOGY

This descriptive-evaluative study made it possible to identify the perceptions of teachers who had followed the Chain of Life training session and who for the majority had taught the program. A total of 40% of them (n=104/263) agreed to complete an online questionnaire, of whom 35% (n=91/263) teach the *Chain of Life Program*. The sample, spread across 15 of 17 of the regions of Québec,¹ is balanced in terms of their experience teaching ESL in Secondary Cycle Two.² Of these, 15 then took part in a semi-structured individual interview, conducted remotely in the language of their choice (French or English). Finally, a focus group interview was held remotely with four specialists, subdivided into two groups (n=2 in French; n=2 in English), recognized in their respective field of health or education.³ While the questionnaire highlighted common, shared values and the one-on-one interview focused on exploring key elements in greater depth, the focus group interview helped situate and clarify a range of information relating to organ and tissue donation on a societal scale.

3. PRESENTATION OF A FEW RESULTS

We are presenting a few results that highlight the perceptions of the teachers who have taught the *Chain of Life Program* (questionnaire⁴/one-on-one interview) and specialists (focus group interview) regarding a) the merits of organ and tissue donation education in schools; b) the effects of the education program on students' learning; c) the impact of organ and tissue donation education in schools on the family.

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1. The two administrative regions in the province of Québec that were not involved at the time of the survey are Gaspésie—Îles-de-la-Madeleine and Nord-du-Québec.
 2. The experience of the participants is broken down as follows: 50 teachers with more than 20 years' experience, 54 with 20 years or less (n=34 with 11–20 years' experience and 20 with 2–10 years' experience).
 3. The experts in the group interview in French were Dr. Pierre Marsolais, an internist and intensivist at Hôpital Sacré-Cœur-de-Montréal from the CIUSSS du Nord-de-l'Île-de-Montréal (founder and president of Dr. Marsolais' Mission) and Ms. Catherine Jolivet, a teacher in France and co-president of the association Al.é.lavie, Alexis, une énergie pour la vie. The group interview experts in English were Ms. Jenny Ryan, Science Communications Specialist at Canadian Blood Services (responsible for education) and Ms. Wendy Sherry, a resource nurse for organ and tissue donation at the McGill University Health Centre (builder of a culture of donation and ambassador for Transplant Québec).
 4. **Questionnaire** – Please note that the participants were asked to indicate their level of agreement on a scale of 1 to 5 (strongly agree, agree, agree somewhat, disagree and strongly disagree) for each item, the results of which are presented below. Given the limited space available, and the fact that very few of them ticked either “disagree” (D) or “strongly disagree” (SD), these are indicated by letters in parentheses.

3.a The Benefits of Organ and Tissue Donation Education in the Classroom

Questionnaire – For the teachers who completed the questionnaire, the relevance of educating young people about organ and tissue donation is clear. The *Chain of Life Program* invariably arouses the interest of both students and teachers and in particular, the teachers report that students appreciate the knowledge acquired (95.61%) and that a dynamic classroom environment is observed when teaching the learning and evaluation situation (LES) (83.51%). Similarly, almost all the teachers (94.50%) said that the education program is perceived as an asset to the English as a second language (ESL) program and three-quarters (74.72%) believe that it should be integrated into the Québec Education Program (QEP) in Secondary Cycle Two. What's more, virtually all the teachers (95.60%) confirm that they like talking about organ and tissue donation in class because they feel it is important to help educate young people about this issue. As well, 81.76% feel that the training provided by the Chain of Life organization is essential in order to teach this program. Table 1 below presents the results.

Table 1

The Benefits of Organ and Tissue Donation Education in the Classroom

	Strongly agree		Agree		Agree somewhat (D and SD)	
Students appreciate the knowledge covered during teaching of the program	38	41.76%	49	53.85%	4	4.40%
	95.61%				(0)	
The LES on organ and tissue donation that students experience in class develops a dynamic climate	34	37.36%	42	46.15%	15	16.48%
	83.51%				(0)	
Organ and tissue donation education is seen as an added value to the ESL program	52	57.14%	34	37.36%	4	4.40%
	94.50%				(1 D)	
Education on organ and tissue donation should be included in the PEQ in Secondary Cycle Two	51	56.04%	17	18.68%	19	20.88%
	74.72%				(4 D)	
Teachers say they like to talk about organ and tissue donation, which helps educate young people about the subject	55	60.44%	32	35.16%	4	4.40%
	95.60%				(0)	
Teachers consider the Chain of Life training essential for teaching the education program	41	45.05%	33	36.26%	14	15.38%
	81.76%				(2 D et 1 SD)	

One-on-One Interview – An analysis of the teachers’ responses during the one-on-one interview leads to the general finding that they all believe unequivocally in the benefits gained by educating students about organ and tissue donation, as well as in the relevance of the education program and the interest it generates among young people (n=15/15). Below are some excerpts from the comments.

Students’ Interest

- Students are very attentive and surprised by a lot of things because it’s a new and stimulating subject. They learn a lot!
- Organ and and tissue donation is an engaging subject for young people and they really get into it.
- The students work in teams and debate their ideas vigorously.

Relevance of the Chain of Life Program

- The LES fosters a climate of mutual sharing between the students and the teacher. It’s extraordinary!
- The turnkey material provided by Chain of Life is well-designed, complete, precise yet accessible, high in quality, easy to use, and motivating for young people.
- No other English units are directly related to saving lives and have a close connection to real people facing real problems whose lives depend on their outcome. We are helping society evolve. We go further than school does; we are changing our world.

Teachers’ Interest

- It’s a current topic of social and societal interest that informs young people and motivates them to become responsible citizens.
- There isn’t enough information about organ and tissue donation in Québec. I’m teaching it so that I can change that.
- We talk about life and death, which is a very meaningful topic, both for my students and for me as their teacher.
- Teaching the education program has changed me by bringing me closer to my students!

Focus Group Interview – During the focus group interview (n=4/4), the specialists identify organ and tissue donation education as a crucial issue for our society. And while they definitely agree that organ and tissue donation education is of the utmost importance for secondary school students, they also target donor families and professional healthcare workers. First of all, regarding the relevance of the education program, Ms. C. Jolivet attributes its excellent quality to the fact that it is “a ‘real teaching sequence’ designed by experienced teachers.” Ms. J. Ryan points out that this program, “so extraordinary, complete and inspiring for students” [...] gives teachers the means to teach about organ and tissue donation, as “it ‘educates’ them to teach.” She adds that the *Chain of Life Program* “sets itself apart from all other programs [...]; its teaching ‘creates young lifelong advocates.’”

In a global vision of organ and tissue donation, Dr. P. Marsolais points out that “education has benefits in all respects and at all levels [...], it’s a question of understanding.” As Ms. W. Sherry explains, “When families have had a discussion on the subject previously, it has a facilitating effect on making a decision in a critical situation.” Ms. C. Jolivet adds that it is necessary to “promote understanding of donation and what donor families and organ recipients go through.” Consequently, both Ms. W. Sherry and Dr. P. Marsolais believe that educating young people is essential, but it is also crucial to educate the general public and healthcare professionals. “It’s a duty” (Ms. W. Sherry)!

3.b Effects of the Education Program on Student Learning

Questionnaire – The *Chain of Life Program* has a formative effect on students. Almost all the teachers (97.80%) who completed the questionnaire said that the program equips teens to make an informed personal decision about organ and tissue donation. As well, more than four-fifths of the respondents (84.62%) agree that the education program is a vehicle for the recognition and development of values like solidarity, generosity and altruism. With regards to health, a similar proportion of teachers (83.52%) believe that bringing this issue into the classroom would have also have a beneficial effect on young people's health by making them more aware of the value of their organs and the need to take good care of them. Table 2 below shows the results.

Table 2
Effects of the Education Program on Student Learning

	Strongly agree		Agree		Agree somewhat (D and SD)	
Students learn everything they need in order to make an informed, personal decision about organ and tissue donation	56	61.54%	33	36.26%	1	1.10%
	97.80%				(1 D)	
Students recognize and develop values of solidarity, generosity and altruism	31	34.07%	46	50.55%	12	13.19%
	84.62%				(2 D)	
Students become aware of the value of their organs and the need to take care of them	21	23.08%	55	60.44%	11	12.09%
	83.52%				(4 D)	

One-on-One Interviews – The one-on-one interview was an opportunity for the teachers to elaborate on the effects of the education program. It is worth noting that while all of them (n=15/15) mentioned the completeness of the information in the education program, enabling students to make an informed decision about organ and tissue donation, each in his or her own way pointed to different formative effects. Here are a few examples of what teachers had to say.

Making an Informed Personal Decision

- As a teacher, I'd say that the education program holds 100% of the students' attention and they ask lots of questions to find out more.
- Students can make an informed decision because they have all the information they need.
- Organ and tissue donation is a sensitive subject from which emotions emerge so it's appealing to listen to them while at the same time provoking questions.
- Students have the opportunity to express themselves and develop critical thinking and their reflections are mature.
- In class, teenagers plead and debate a cause. They feel concerned by human problems and suffering.
- Young people make decisions by giving their consent, but some have to “fight” at home for their parents' approval. They learn to take a stand on something they care about deeply.

Recognition and Development of Values

- Students understand that organ and tissue donation is not only about respect and giving, but also a commitment to their values, sincerity and authenticity.
- The education program encourages young people to be open, to listen to different points of view and have respect for each other's decisions and empathy for others.
- The LES really stimulates students. It goes beyond the teaching of ESL by touching on notions of health, citizenship and the well-being of self and others.

Health

- Students learn that their organs have “a health of their own.”
- At this age, young people understand how lucky they are to be healthy.

Focus Group Interviews – The encounter with the experts during the focus group interview (n=4/4) shows the impact of understanding a sensitive issue, leading to responsible citizenship. Ms. C. Jolivet shares that “thinking about organ and tissue donation gives meaning to life.” For her, “Education is a fundamental element of lifelong community spirit.” As Ms. W. Sherry explains, dealing with organ and tissue donation in the classroom is “an amazing and empowering moment for [the students] and something that they’re never going to forget and which will permit them to move forward.” According to her, teens “are willing to debate everything because, at this age, they’re ready and able to question everything. They’re trying to learn more about themselves—and the education program is an excellent way to do so—but also to find out what they want to be and what they want to stand for.” Dr. P. Marsolais, points out that “young people want to change the world. The better informed they are, the better educated they are and the better society will be.” In short, the *Chain of Life Program* “helps shape the next generation of policy- and decision-makers” (Ms. C. Jolivet). As Ms. J. Ryan emphasizes, the reason is that students and teachers “are involved in something really important that gives back to the community. Chain of Life is a fantastic example of an extraordinary and inspiring program that makes a lasting impression on people for a long time to come”!

3.c The Impact of In-school Organ and Tissue Donation Education Within the Family

Questionnaire – Organ and tissue donation education in schools not only reaches students, it also has an impact on their parents. The teachers who completed the questionnaire agree that a transfer of knowledge and learning takes place from school to home through family discussions (78.03%) and these exchanges don’t seem to worry parents (73.62%). What's more, 72.53% of the teachers believe that young people would act as ambassadors for the family discussions. Table 3 below outlines the results.

Table 3
Effects the Education Program Has on Families

	Strongly agree		Agree		Agree somewhat (D and SD)	
Students discuss the subject as a family	22	24.18%	49	53.85%	20	21.98%
	78.03%				(0)	
Parents don't seem worried by the family discussions	52	57.14%	15	16.48%	15	16.48%
	73.62%				(2 D and 7 SD)	
Students assume the role as ambassadors	22	24.18%	44	48.35%	17	18.68%
	72.53%				(8 D)	

One-on-One Interviews – During the one-on-one interviews, the teachers indicated that while they were sure that virtually all of their students had exchanged information with their parents, all of them confirmed that they were aware that most of them had discussions with their parents at home (n=15/15). As an example, here are a few statements made by individuals.

- Parents told me that their children had shared this serious subject with them.
- Students were eager to talk about it with their families, but also with their peers.
- Parents thanked me for talking about it. Their child is said to have encouraged them to become a donor, and every member of the family reportedly signed his or her organ and tissue donation consent card.

While there is no consensus on the term “ambassador,” given the variety of actions it can engender, three quarters of those interviewed noted that students have discussions with each other, express their opinions and defend their positions. Thus, organ and tissue donation appeals to them! Finally, one teacher stated that, “as citizens and members of society, the entire population should have access to the essential information provided by the *Chain of Life Program*.”

Focus Group Interview – During the focus group interview with the experts (n=4/4), Dr. P. Marsolais states that “the more that families and individuals in general are educated, the less refusal there will be because people will understand the importance of organ and tissue donation. We need to take the time to explain it to them!” As Ms. C. Jolivet stresses, “It’s essential for donation to make sense to families,” so education is a must. For her part, Ms. J. Ryan mentions that providing explanations to students also contributes to reaching parents, insisting that “Education is very important.” She believes that addressing this issue in schools “helps educate a young generation for a better future.” In the same vein, in addition to the direct and immediate effects on students and their families, Ms. W. Sherry discusses the “generational transferability” of learning (knowledge, know-how and interpersonal skills), since “today’s young ambassadors will become tomorrow’s parents.” More specifically, Ms. J. Ryan explains that “it’s not just a matter of deciding to become an organ donor, but also about helping others become informed and passing on the access to information [...] to those who need it.”

CONCLUSION

Education, especially that of young people, is proving to be a powerful driving force in establishing a culture of organ and tissue donation in Québec. According to the organization Chain of Life, the government should therefore invest in education.

Thanks to Chain of Life's innovative program and expertise, Québec could become a world leader in organ and tissue donation education, thereby creating an exemplary model for society. In addition, it could mobilize the Québec population toward a more altruistic and healthier culture by harnessing the power of young people as agents of change, thus helping save more lives.



EDUCATION
AND TISSUE
DONATION:

YOUTH MADE **AWARE**
WELL-INFORMED **FAMILIES**
MORE LIVES SAVED



CHAIN OF LIFE IS...



A Mission to Serve Life

Chain of Life is an organization that helps save lives and improve the quality of life of others who are ill, through its unique education program on organ and tissue donation.



A Vision for a Culture of Donation and a Healthy Society

That the *Chain of Life Education Program* be taught in all secondary schools in Québec (and even elsewhere) to help save more lives by leveraging **the power of young people as agents of change!**

Chain of Life Makes Headlines in Québec and Elsewhere

An education program that is generating a great deal of interest beyond our borders, with a golden opportunity to position Québec as the leader in organ and tissue donation education.

Media coverage throughout Québec thanks to the Chain of Life Challenge and the Chain of Life Walk organized by certain schools.

A motion before the Québec National Assembly in 2009 and one before the House of Commons in Ottawa in 2018.

A program for which the founding president has received numerous awards, including the *Prix Ambassadeur* from Transplant Québec, the *Prix en éducation* from the Université de Sherbrooke, an award at the national level from the Kidney Foundation of Canada and the H. H. Stern Award from the Canadian Association of Second Language Teachers (CASLT) in recognition of innovative teaching practices.

The Chain of Life flag has reached the highest peak on every continent in the world, including Everest!

"A sincere thank you to the Chain of Life teachers in Québec for leading the way and becoming a beacon for all of Canada."

— Canadian Blood Services

A Leading Education Program

Featuring a holistic, intergenerational approach, the *Chain of Life Program* educates young people aged 15–17 about organ and tissue donation during their ESL classes. The learning and evaluation situation (LES) is built around stimulating activities interspersed with up-to-date scientific information, moving testimonials and true stories.

The goal is not to convince students, but to inform them about an important social issue. It enables young people to make an informed personal decision about organ and tissue donation. They are then encouraged to act as responsible citizens by becoming ambassadors for family discussions, thereby helping save more lives.



Quality Training

The one-day training prepares teachers to teach the *Chain of Life Program*. In addition to giving them a good overview of the material and an approach to follow, the training answers many questions, dispels fears and helps people network. It's a dynamic training that elicits rave reviews from all concerned.

"There is currently nothing comparable in terms of depth of the content for students of this age. This learning tool is unifying, brilliant and up to date, enabling students to learn language while reflecting on a reality that leaves no one indifferent. The use of technological tools brings added value to this excellently developed education program. It's truly a marvellous project!"

— Hélène Boucher, professor/lecturer at
Université du Québec Outaouais



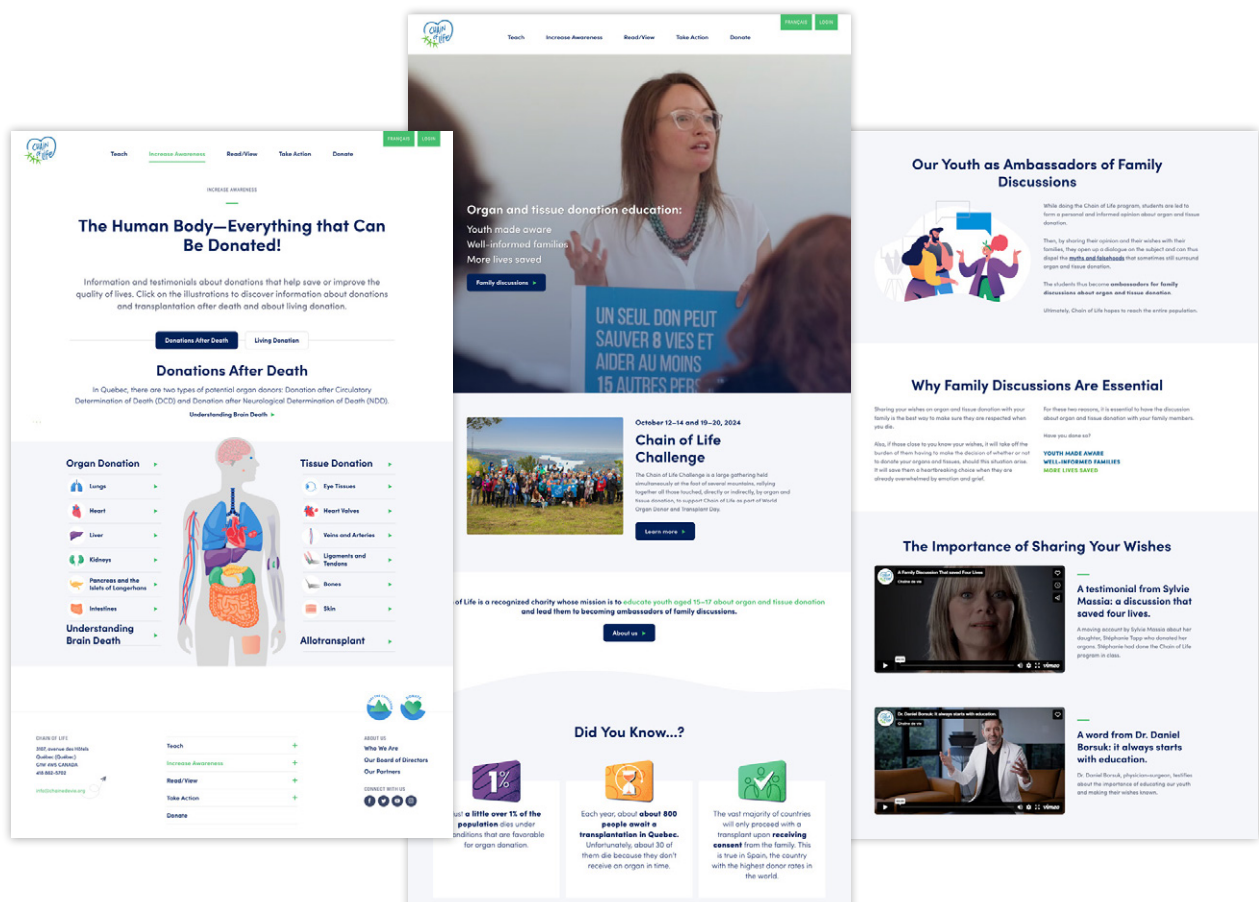
Innovative Teaching Material

A top-quality pedagogical toolkit on organ and tissue donation is distributed free of charge to participants during the training. A turnkey material, developed over a period of seven years by a team of experienced educators, with the collaboration of Transplant Québec for the validation of the medical and scientific content.

A Bilingual Website Rich in Information and Testimonials

The Chain of Life website was developed through donations collected in part during the Chain of Life Challenge. There you'll find, among other features, informative texts, short videos by leading transplant specialists and touching testimonials.

chainoflife.org



Organ Donation Education: A Lever of Action for the Adoption of Healthy Lifestyle Habits

In the course of their learning, students are also made aware of the inestimable value of a healthy body and the importance of taking care of it by opting for healthy lifestyle habits.

In a context where the demand for organs for transplantation far exceeds the supply, it is essential to address the health problems that affect our vital organs and that are often linked to poor lifestyle habits. One of the driving forces behind the health component of the *Chain of Life Program* is the awareness that the scarcity of organs increases their value, making it all the more important to keep them healthy.



Thus, Chain of Life aims not only to bring young people to become ambassadors of family discussions about organ and tissue donation, but also to mobilize as ambassadors for the adoption of healthy lifestyle habits.



Young ambassadors rallying together throughout Québec



“The Chain of Life LES absolutely blew me away! First of all, there are touching stories based on real cases. These stories make us realize that accidents happen so quickly and that it’s our duty as children to talk to our parents about organ donation so that if something unfortunate happens to us, they will make the decision we would have wanted. I was surprised to learn that doctors will always approach the families.

In fact, the unit never ceased to surprise me from beginning to end. I’d like to thank the people who created the *Chain of Life Program* because it’s been a lot of fun learning. I hope that all students in Québec get the chance to experience this project because it allows us to talk about a subject that saves lives.”

— Florence Ouellet, student at École de Mortagne, Boucherville

“Chain of Life instills in students and their families knowledge about health and organ donation that also provides them with a lifelong altruistic mindset. Just think of what a society like this could accomplish!”

— Dr. Damian Fogarty, Consultant Kidney Physician, Belfast, Northern Ireland

TESTIMONIALS



One Teacher's Perspective

A vibrant testimonial from a Chain of Life teacher



Why teach the *Chain of Life Program*?

The *Chain of Life Program* as experienced by key players: including a teacher and her students. Explanations and testimonials that speak for themselves. (In French)



A Family Discussion Saves Four Lives

Ms. Sylvie Massia's moving account about family discussions and the importance of organ and tissue donation education in schools. Her daughter Stéphanie saved four lives.



Interview with Dr. Daniel Borsuk

Dr. Daniel Borsuk, a medical surgeon, speaks about the importance of organ and tissue donation education.

RECOGNITION AND SUPPORT FOR CHAIN OF LIFE (2008–2024)

2008	École secondaire de Rivière-du-loup and Centre de services scolaire Kamouraska–Rivière-du-loup	<ul style="list-style-type: none"> Chain of Life partners since the beginning
	Mr. Mario Dumont, deputy and Leader of the Opposition	<ul style="list-style-type: none"> Motion in support of Chain of Life at the Québec National Assembly
2009	<i>Fédération des commissions scolaires du Québec (FCSQ)</i>	<ul style="list-style-type: none"> Letter of support Presentation for school principals
	Société pour le perfectionnement de l'enseignement de l'anglais, langue seconde, au Québec (SPEAQ)	<ul style="list-style-type: none"> Teacher of the Year award (in ESL) presented to Ms. Lucie Dumont
2011	Transplant Québec	<ul style="list-style-type: none"> TQ becomes a partner of Chain of Life
2014	Regroupement des responsables de l'enseignement de l'anglais, langue seconde (RREALS)	<ul style="list-style-type: none"> Letter of support Presentation of Chain of Life to members
	Regroupement des conseillers et conseillères pédagogiques de l'enseignement de l'anglais, langue seconde (RCCPALS) [Two organizations for ESL education advisors in Québec]	<ul style="list-style-type: none"> Help targeting teachers Full cooperation in organizing training sessions in schools
2015	Société des écoles du monde du BI du Québec et de la francophonie inc. (SÉBIQ)	<ul style="list-style-type: none"> Letter of support Invitation to present Chain of Life and offer a training session during SÉBIQ's annual convention
	Université de Sherbrooke	<ul style="list-style-type: none"> Award in education
2017	<i>Société d'action nationale de Rivière-du-loup</i>	<ul style="list-style-type: none"> Nomination of Ms. Lucie Dumont, <i>Patriote de l'année</i> for her involvement in a crucial issue for our society: organ and tissue donation education
2018	Transplant Québec	<ul style="list-style-type: none"> Ambassadeur du don d'organes award presented to Ms. Lucie Dumont
	NHS Transplant Forum, Belfast, Northern Ireland	<ul style="list-style-type: none"> Keynote speaker to present Chain of Life
	Apple, IBM, Rotary International, Lions Club International, <i>Association féministe d'éducation et d'action sociale (Afeas)</i> , etc.	<ul style="list-style-type: none"> Several requests to present Chain of Life
2019	Mr. Bernard Généreux, federal deputy	<ul style="list-style-type: none"> Declaration of support in the House of Commons
	<i>Métro</i>	<ul style="list-style-type: none"> Gala Top Personnalités Award in the category Education
2020	Kidney Foundation of Canada	<ul style="list-style-type: none"> Recognition award at the national level
2021	Musée de la civilisation (October 2021–2022)	<ul style="list-style-type: none"> Showcasing of Chain of Life in the exhibition, <i>Generosity. From the Heart</i>
2021	Canadian Blood Services (CBS)	<ul style="list-style-type: none"> Article featuring Chain of Life

2022	The City of Rivière-du-Loup	<ul style="list-style-type: none"> Yves-Godbout Municipal Award presented to Ms. Lucie Dumont for her involvement, gift of self and impact on the community
2023	Canadian Association of Second Language Teachers (CASLT)	<ul style="list-style-type: none"> H. H.-Stern Award presented to Ms. Lucie Dumont in recognition of her innovative teaching practices
2024	Katia Chapoutier, France Télévisions (with the participation of Chain of Life)	<ul style="list-style-type: none"> Documentary France-Québec, <i>Passeurs de vies</i> (issues related to organ donation, the importance of family support and education) / Airing in France on October 17, 2024, to mark the World Organ Donor and Transplant Day.



Lucie Dumont reviving the Yves-Godbout Municipal Merit Award (2022)



Lucie Dumont at the NHS Transplant Forum, Belfast, Northern Ireland (2018)

Letters of Support

- *Fédération des comités de parents du Québec (FCPQ)*
- Justin Trudeau, Prime Minister of Canada
- Sébastien Schneeberger, député from Drummond—Bois-Francs
- Marie-Josée Raboisson, cardiologist and director of the transplant and heart failure program at *CHU Sainte-Justine*
- Dr. Frédérick D'Aragon, intensivist anesthesiologist at CHUS
- Ms. Sara Lemieux-Doutreloux, resource nurse, CIUSSS-CHUS
- Canadian Blood Services
- Dr. William Wall

Video Testimonials

A wealth of testimonials from doctors, transplant patients, donor families, teachers and students

FINANCIAL SUPPORT AND FUNDRAISING FOR CHAIN OF LIFE (2008–2024)

École secondaire de Rivière-du-Loup (2008–2013)	\$10,000
Bas-Saint-Laurent Regional directorate–MELS (2008)	\$1,000
CSS Kamouraska–Rivière-du-Loup: payroll contribution (2014)	\$30,000
Transplant Québec (2011)	\$5,000
Desjardins sponsorship as part of a Transplant Québec–Chain of Life partnership (2013)	\$250,000
Ministry of Health and Social Services (2013)	\$31,000
Kidney Foundation of Canada (2013)	\$10,000
<i>Secrétariat à la Citoyenneté</i> (2013)	\$1,500
<i>Léone Ouellet</i> –Rivière-du-Loup (2014)	\$30,000
Private donations from Rivière-du-Loup citizens (2013–2014)	\$77,500
CSS Kamouraska–Rivière-du-Loup	\$30,000
Transplant Québec	\$30,000
Telus (2018)	\$20,000
<i>Fondation Saint-Hubert</i> (2005 and 2019)	\$27,500
<i>Fondation Claire et Jean-Pierre Léger</i> (2019)	\$12,500
IBM (2019)	\$12,500
Chain of Life Challenge fund-raising activities (2015–2023)	\$320,000
<i>Fondation Famille Léger</i> – Partner of Chain of Life (\$250,000 over 5 years, from 2020–2024)	\$250,000
Canadian Blood Services (CBS)	\$50,000
Fondation GDG (2021)	\$5,896
Mr. Denis Tardif, deputy from Kamouraska–Rivière du Loup (2022)	\$2,000
Mr. Christian Dubé, Minister of Health and Social Services (2022) et des Services sociaux	\$2,000
Fundraising dinner for Chain of Life in honour of Catherine and Jérémy by Thetford student, Felix Tanguay (2022)	\$1,200
Biking Across Canada: <i>On roule pour Chaîne de vie</i> (2022)	\$10,300
TOTAL in sponsorships, donations and financial support	\$1,249,896



FOR THE RESPECT OF FREE AND INFORMED CONSENT TO ORGAN AND TISSUE DONATION

Chain of Life rises with conviction for the sacred principle of free and informed consent in the field of organ and tissue donation. Consent, the cornerstone of our society, transcends all circumstances, even beyond life itself.

The model of presumed consent, which authorizes the removal of organs in the absence of an explicit refusal, undermines the fundamental values that guide our society. We believe it is crucial to reiterate that organ donation must always remain an altruistic gesture based on free choice.

A Powerful Example

Let's take example from the powerful *MeToo* movement, a movement, which has reminded the entire world of the imperative of clear consent in all human relationships. Consent cannot be presupposed, whether in personal interactions or in the medical context of organ donation. Inspired by the *MeToo* movement, Chain of Life underscores the essence of consent in our society and in our healthcare system.

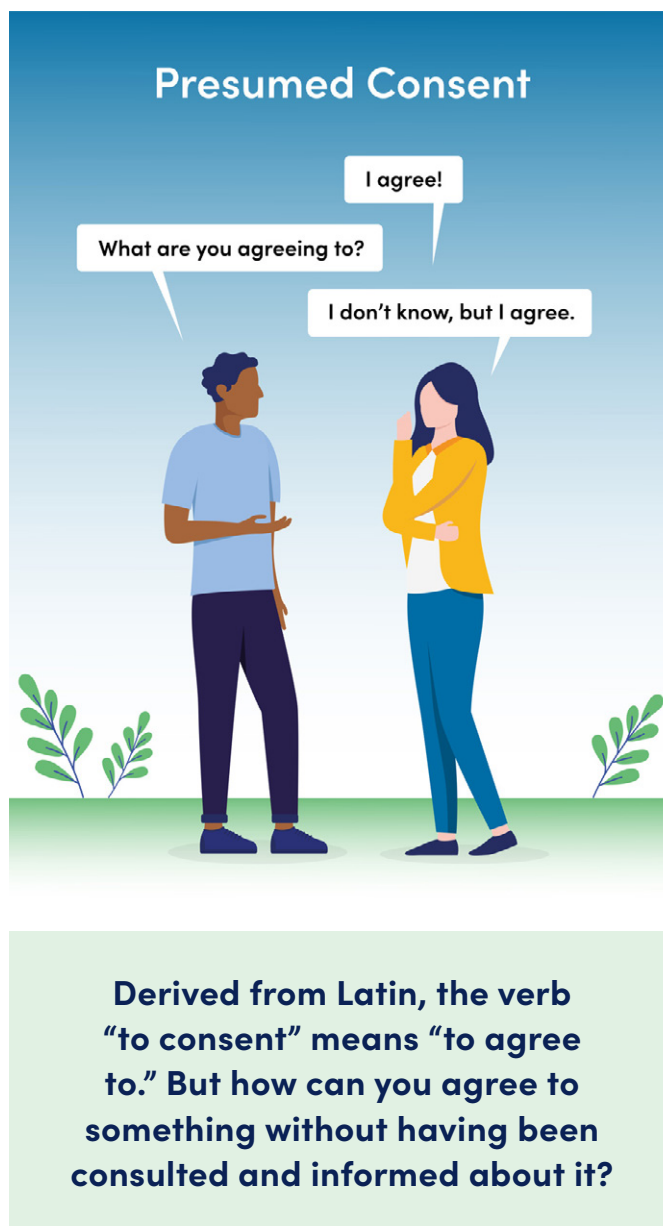
The right to complete information and free and informed consent, rooted in the principles of autonomy and human dignity, now permeates all areas of healthcare law. It is imperative to strengthen the implementation of this right, in particular by ensuring the transmission of clear, relevant information.

A Conscious and Voluntary Act

Presumed consent could jeopardize the autonomy of individuals and undermine public confidence in the organ transplantation system. We cannot allow consent to organ donation to become an obligation by default rather than a conscious and voluntary act of generosity.

Decisions regarding organ donation must remain in the hands of individuals and their families, and in full knowledge of the facts.

We advocate a solidarity-based society that demands a free and informed response from each individual during his or her lifetime. Consent can only be a freely chosen gesture. Respect for consent is essential for a society that respects individual rights and ethics.



Ethical and Legal Shortcomings

Many experts (lawyers, ethicists, and sociologists) have pointed out the ethical and legal shortcomings of presumed consent. It is difficult to ascertain whether the absence of opposition reflects acceptance or agreement with organ removal, or simply indifference or a lack of information about donation and the procedures for refusal. When it comes to organ donation, silence cannot under any circumstances be interpreted as consent. Pressure to impose organ donation would only serve to discourage people from actively participating in this noble cause.

Chain of Life supports any action or measure aimed at preserving free and informed consent to organ and tissue donation and promoting absolute respect for individual rights and human dignity.

Together, let's not accept that consent be relegated to a simple presumption.

Nothing at All¹

Donation involves a **voluntary act, a personal choice guided by values like generosity and compassion**. When the government decides that we are all organ donors by default, it changes the nature of donation fundamentally. It is then no longer a voluntary act of giving, but a legal obligation, fundamentally changing the very meaning of organ donation.

The story told by Dr. Élisabeth Lepresle, a retired anesthesiologist with a doctorate in philosophy, clearly illustrates the tension between giving and taking in the context of presumed consent.

"It all started with a short film made a few years ago by the French Transplant Organization, a little story about 'nothing' at all. A child explains what a transplant is... "There's a child who is going to die... They're going to take his kidneys." And spontaneously, this idea comes to mind: "If they take his kidney, it means that he's not giving it away."

Many of the families I have met with following a death made similar comments to me as I attempted, no doubt awkwardly, to obtain the non-objection of the deceased. Did he say that he did not wish to donate his organs? And the family's response: "When he was alive, he wanted to donate a kidney to his best friend, but it was against the law. And now that he's dead, you come and tell me that it's legal to take his organs and transplant them in whomever you want." Giving and taking are once again at odds here." (Lepresle, 2006, 179)²

"What is a gift then, if we don't do the giving?"

1. Free translation of "Un rein du tout." Play on the French words "rein" (kidney) and "rien" (nothing).

2. Speech given in Paris on June 17, 2006, on the first study day organized by Carina Basualdo, as part of the International and Interdisciplinary Research Network on "Organ Donation and Transplantation." and "Interdisciplinary Research Network on Organ Donation and Transplantation," Lepresle, É. (2006). "Le consentement présumé du donneur, un paradoxe du langage," *Essaim*, no. 17, pp. 179–188. <https://doi.org/10.3917/ess.017.0179>

Opt-out legislations: the mysterious viability of the false

Rafael Matesanz¹ and Beatriz Domínguez-Gil¹

It is frequently assumed that opt-out legislations set down a more favorable scenario to organ donation than do opt-in legislations. However, there are no clear examples of countries with a real sustained increase in organ donation after modifying the law. Arshad *et al.* performed a comparison that shows no significant differences between countries with these 2 legal systems. Health care providers must focus on actual barriers to increasing organ donation rather than on presumed consent alone.

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[see clinical investigation on page 1453](#)

More than a century ago, the great surgeon-philosopher Wilfred Trotter amused us with “the mysterious viability of the false” (p. 561)¹:

Belief of affirmations sanctioned by the herd is a normal mechanism of the human mind and [...] totally false opinions may appear to the older of them to possess all the character of rationally verifiable truth, and may be justified by secondary process of rationalization which it may be impossible directly to combat by argument. When an experience does not fit the shared assumption of their herd, humans tend to evade the experience and the evidence of it.

This phenomenon has been applied to several medical items such as the distinction between normotension and hypertension, but it can be perfectly used for the frequent assumption that opt-out legislations set down a more favorable scenario to organ donation than do opt-in legislations. The main

consequence is an eternal public and political discussion in many countries with an opt-in system in place about the potential benefits of moving to a presumed consent policy. Recent examples of such changes or announcements of changes are those of Argentina, Colombia, Scotland, The Netherlands, or Wales, with a possible future change in some other countries such as England. Politicians who promote this kind of legislative reforms often contemplate them as a magic tool that will boost organ donation in their country, with mass media contributing to spreading the idea.

Surprisingly, the only example of a country with clear positive results after a change in legislation was Belgium more than 30 years ago.² However, the Belgians have (besides and together with the opt-out law) one of the best donation systems built on the figure of donor coordinators, which has progressively increased donation rates. There is no other example of a country with a real sustained increase in organ donation after modifying the law, besides some initial and temporary increases, which can be better attributed to the fact that debates about shifting toward a presumed consent policy may bring the topic of organ shortage to the public attention. We should not forget that organ

donation is multifactorial. Communication with the public is crucial, and “to move the water” in any possible way is usually a good means to promote it, at least in the short term.

The cases of Chile, Singapore, and Sweden are good examples of failure to improve organ donation with the adoption of opt-out laws. Even more, in February 1997 Brazil introduced a “hard” form of presumed consent that did not require the consent of the family. In response to widespread public and medical disquiet, the legislation was amended to make consultation with the family mandatory, but by then the damage had been done and the legislation was entirely revoked in October 1998.³

When comparing opt-in with opt-out countries, published experiences are contradictory in their conclusions, partly because they use different methodologies⁴ or fail to define clearly if a specific country has a real opt-out policy or not. This is the case of Spain, the country with by far the highest organ donation rates since 1992, with 48 donors per million population in 2018 (Figure 1). It is frequently cited as an example of the advantages of presumed consent because of the theoretical opt-out law in place since 1979. However, it was not until 1989—10 years after the legislation was issued—that donation rates started to increase in our country after the implementation of the so-called Spanish Model on Organ Donation and Transplantation.⁵ Furthermore, the Spanish law sets only a theoretical presumed consent, because in practice the system is “opt-in” and the effect of the type of consent on donation is considered insignificant. An assessment must be made of the wishes of the person toward posthumous donation expressed by any means during their lifetime. This includes an interview with relatives of potential organ donors to determine whether donation was consistent with the individual’s wishes and values. In the end, family’s wishes are always final and organ recovery does not take place if this is not

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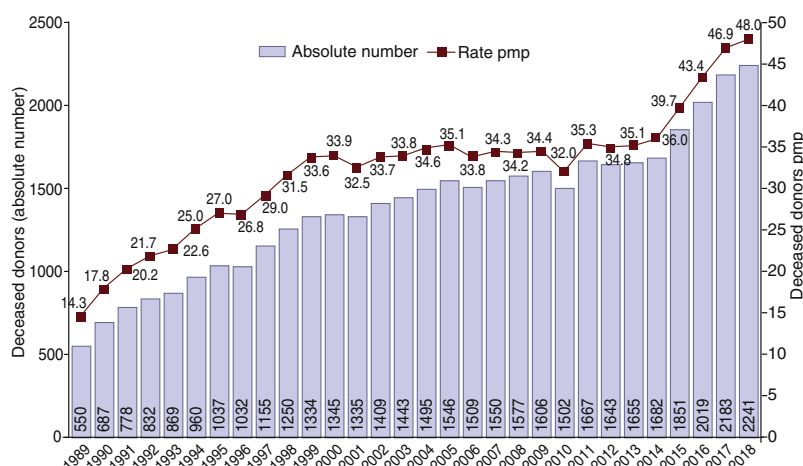


Figure 1 | Deceased donation rates in Spain, absolute number and rate per million population (pmp), since the start of the Spanish National Transplant Organisation (1989) until 2018.

acceptable to the family.^{5,6} Crucially, Spain does not have an opt-out register for those who do not wish to become organ donors.⁶ Therefore, the Spanish approach is not substantially different from that in opt-in realities.⁷

To the contrary, infrastructure, organization around the process of deceased donation, and continuous innovation are deemed the keys for success.⁸ In fact, the Spanish results derive from a specific organizational approach to the process of donation after death to ensure the systematic identification of opportunities for organ donation and their transition to actual donation as well as to promote public support to the donation of organs after death.^{5,8} The high deceased donation rates in Spain are to be highlighted in the context of the dramatic decline in the incidence of brain death and the changes in end-of-life care practices in the country since the beginning of this century. This prompted the system to conceive new strategies to increase the availability of organs for transplantation: (i) promoting the identification and early referral of possible organ donors from outside the intensive care unit to consider elective nontherapeutic intensive care and incorporate the option of organ donation into end-of-life care, (ii) facilitating the use of organs from expanded criteria and

nonstandard risk donors, and (iii) developing the framework for the practice of donation after circulatory death.⁸ With these measures, organ donation has raised an additional 37% during the last 5 years and reached 48 donors per million population (even 2 regions are >80 donors per million population), showing once more that organizational measures are always the key to improve organ donation.

In this issue, the study by Arshad *et al.*⁴ performed a comprehensive and contemporary comparison between 35 Organisation for Economic Co-operation and Development developed countries with opt-in and opt-out legislations, adjusted for country-specific socioeconomic factors that could confound organ donation/transplant activity rates. Furthermore, to avoid the important bias that represents the inclusion of Spain in the opt-in group, they made the analysis both with and without this country. In both cases, the authors could not find significant differences in deceased donation rates or in renal, nonrenal, and total transplantation rates. A key aspect of this study compared to other studies was its methodological approach because countries compared have no significant socioeconomic differences that can influence the results. We cannot but applaud the authors' conclusion that health care providers must focus on actual barriers to

increasing organ donation rather than on presumed consent alone.

Arshad *et al.* also found that opt-out versus opt-in countries have significantly less living-donors per million population. In a multivariate linear regression model, opt-out is independently associated with less living donors but not with deceased donation or any transplantation activity. This is consistent with the findings of other studies,³ and certainly, it is not easy to explain. Sociocultural attitudes, public health initiatives, or economic implications can partly justify these differences. The authors stated (p. 1367):

[T]here are numerous pitfalls with regards to insufficient control for confounders or selection bias that can affect observed associations such as the link between opt-out countries and reduced living donor rates. However, this aligns with our take-home message that the situation on the ground is too complex to simply link opt-out or opt-in directly with organ donation rates or solid organ transplantation activity.

In summary, the evidence does not support that shifting toward presumed consent will solve organ shortage. But still today, this measure is seen as a

magic solution that departs from the conviction that low deceased donation rates result only from a negative public attitude and a poor contribution of society. It results from ignoring that the key for success lies within the health care system. But we should “...never blame the population. If people donate less, it must be something we have done wrong” (p. 2575).⁹

DISCLOSURE

All the authors declared no competing interests.

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