



Give Life Alberta

Annual Report 2023



**GiveLife
Alberta**



**Alberta Health
Services**

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Donation and transplant staff on Green Shirt Day

Message from Our Leaders

Looking back at the past year reminds us of how fortunate we are to have such passionate teams committed to a life-saving cause. This has been a transformative year for organ and tissue donation in Alberta, and we are proud to share our program's evolution and accomplishments with you in this report.

The amended *Human Tissue and Organ Donation Act* of April 2023 transferred many donation-related provincial responsibilities to Alberta Health Services. The newly formed Alberta Organ and Tissue Donation Program (AOTDP) united five dedicated healthcare teams in Edmonton and Calgary, with a provincial office to guide the program toward improving donation opportunities in all AHS facilities. AOTDP is now "Give Life Alberta".

The new amendments also created "Mandatory Referral" which requires medical practitioners to refer all dying patients who could be eligible to donate organs or tissues to a donation organization. Physicians from the Specialist in End-of-Life Care, Neuroprognostication and Donation (SEND) Program continued to work closely with healthcare teams ranging from critical care to emergency to neonatology, helping to identify and care for potential organ donors. These efforts contributed to a marked increase in referral and approach rates; at the start of the SEND Program in 2021, the referral rate for eligible potential organ donors was less than 40% and the approach rate was 72%. By the end of 2023, these had risen to almost 60% and 90% respectively.

2023 has been a transformative year for organ and tissue donation in Alberta.

Avoiding missed donation opportunities is among the most important parts of any organ and tissue donation program. Ensuring every eligible patient has the option to donate not only saves more lives, but can also offer donor families some peace of mind after a devastating loss. The rate of missed organ donation opportunities has steadily declined in Alberta over the past 2½ years, from approximately 25% in the latter half of 2021 to less than 10% throughout 2023.

Organ and tissue donation brings life from loss; one organ donor can save up to eight lives, and a tissue donor can save or dramatically improve the quality of life for up to 75 people. We are incredibly grateful to our donor families for granting Alberta another record year – with 273 organ and tissue donors. However, there are still almost 300 people waiting for

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life-saving transplants. Nearly 50 people on the waiting list died in 2023. Clearly, we have much more work to do, and the steps taken in the past year are a foundation for increasing access to – and options for – precious gifts of life across our province.



Deanna Paulson
Operational Director
Give Life Alberta



Dr. Andreas Kramer
Medical Director
Give Life Alberta

About Give Life Alberta

The Human Tissue and Organ Donation (Mandatory Referral) Amendment Act enables Alberta Health Services (AHS) to carry out activities on behalf of the Alberta Organ and Tissue Donation Agency (Agency) of Alberta Health. Give Life Alberta was subsequently created as a department within AHS, uniting all existing organ and tissue donation teams under a single name and brand. Additionally, a strategic provincial office was created to ensure all responsibilities of the Agency were met, and to be accountable for provincial strategic initiatives to optimize organ and tissue donation. Duties of the Give Life Alberta provincial office include:

- ♥ Consult, coordinate and support the work of donation organizations in Alberta.
- ♥ Monitor and measure information about organ and tissue donation and related services.
- ♥ Educate the public and health care community about tissue and organ donation.
- ♥ Support and encourage use of the Alberta Organ and Tissue Donation Registry.
- ♥ Make recommendations to the Minister of Health and provide regular system performance reports.
- ♥ Receive submissions from individuals and groups related to the Agency's purpose.

The provincial program is led by an Operational Director and Medical Director, and has nine full time staff including: Program Manager, Administrative Supports, Senior Donation Consultants, Senior Communications Advisor, and Senior Analyst.

The program is governed by a Steering Committee and an Advisory Committee. The Steering Committee is comprised of administrative and medical leadership from stakeholder groups including organ and tissue donation, transplantation, critical care, emergency, pediatrics and medical assistance in dying, with broad geographic representation covering urban and rural communities. The Advisory Committee is comprised of patient and family advisors, community partners, Indigenous Wellness representation, SEND Physicians, critical care, emergency, medicine, surgery, pediatrics, neonatology and spiritual care.

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Building on the foundation of the existing donation program, Give Life Alberta has developed a strategic plan within the AHS framework, and is now poised to advance organ and tissue donation in Alberta to new levels of excellence, improving patient and family care and enhancing access to transplantation.



Richard Bourgeault and Nicole Fraser with their son, Karter. The six-year-old became a tissue donor in 2023. Read more about the family's story on page 7.

Donation Metrics

Organ Donation

Metric	2021	2022	2023
Eligible Deceased Organ Donors	286 ¹	265	366
Referred Deceased Organ Donors	106 ¹	128	216
Actual Deceased Organ Donors	68	97	103
Deceased Donors per Million Population	15.9 ²	21.7 ²	21.5 ²
Consent Rate	38% ¹	48%	33%
Living Organ Donors	79	74	72
Organ Transplants	404	491	474

Tissue Donation

Metric	2021	2022	2023
Referred Deceased Tissue Donors	985	868	1,081
Actual Deceased Tissue Donors	232	181	198
Deceased Donors per Million Population	53.5 ²	40.5 ²	41.3 ²
Consent Rate	-	-	-
Living Tissue Donors	47	28	33
Allografts Distributed	4,025	4,923	4,047

¹ Estimated from partial year data. Medical record review program commenced mid-2021.

² Slight discrepancies in Deceased Donors per Million Population figures reported by different agencies are due to varying population estimates and are immaterial.

³ See Appendix I for data definitions.

Life from Loss

Karter Bourgeault's grieving parents find comfort in helping other families

A six-year-old Edmonton boy has saved the lives of two babies – by donating his heart valves after his death.

Karter Bourgeault was diagnosed with *diffuse intrinsic pontine glioma* (DIPG), a rare and aggressive brain tumour, in July of 2022. On September 26 of that year, he spent his sixth birthday in radiation treatment. In total, the little Edmonton Oilers fan endured more than 30 rounds of radiation at the Cross Cancer Institute, where staff tried to lift his spirits with what he enjoys most.

“He got two radiation masks because he went to radiation twice,” explains his father, Richard Bourgeault. “The first one was a Connor McDavid mask, then he met (Edmonton Oiler) Tyson Barrie during school and he wanted a Tyson Barrie mask.”

Life expectancy after a DIPG diagnosis is less than two years. Karter deteriorated from a happy child who loved to swim, wrestle with his dad and play ninjas – to no longer being able to walk or talk. He was accepted into a clinical trial for a new treatment in New Jersey which relieved some of his pain, but he had seizures and was transported back to Edmonton.

In July of 2023, one year after his diagnosis, Karter died at home in his parents' arms.

“One thing that Richard and I decided from the minute that we got his diagnosis is that this wasn't going to be for nothing,” says his mother, Nicole Fraser. “We weren't going to let our son suffer, pass away for no reason. We wanted to be able to help any way that we can.”



Richard Bourgeault and Nicole Fraser hold their son Karter's donor medal.



Karter Bourgeault

Karter's parents donated his brain and tumours to DIPG research, as well as his heart valves to the AHS Comprehensive Tissue Centre (CTC). His valves were transplanted into two babies with heart defects, saving their lives.

"With children and babies, (heart valves are) a very rare donation that we get," says CTC supervisor, Candice Bohonis. "It's a very hard decision for a parent to make at the time of death... it's a tragic, horrible time in their lives, but the parents who do choose donation find a lot of value and comfort with donating those tissues. And it helps specifically other babies and children, which helps (donor) parents through their grief as well."

There is a constant shortage of tissues for patients who need them across Canada. While only one to two per cent of people are eligible to donate organs after they die, most can be considered for tissue donation, including patients with cancer.

Tissues that can be donated include eyes, bone, connective tissue and placenta, along with skin and heart valves which can be life saving. All tissue banks across Canada are always short on pediatric-sized heart valves.

Karter's parents have found a bit of comfort in knowing their boy saved two babies, preventing profound pain for other families. "For myself, it gives me a little bit of peace to know he was able to (donate)," says Nicole. "(Recipients) could have a longer life... no child should have to lose their life at six-and-a-half years old or any young age. And no parent should have to bury their child."

"If I can help someone else, maybe their kid lives," adds Richard. "I wanted to donate everything I could, to keep as much of (Karter) alive as possible."

"It gives me a little bit of peace to know (Karter) was able to donate," says his mother Nicole.

To learn more about organ and tissue donation, visit [GiveLifeAlberta.ca](https://www.givelifealberta.ca).

The SEND Program

In 2018, leadership of the AHS organ donation programs submitted a proposal to Alberta Health for implementation of a donation specialist physician program. It was recognized that for donation specialist physicians to have maximum impact, it would be crucial to effectively integrate their responsibilities into existing processes of patient care delivery.

The SEND team consists of 27 intensive care physicians across Alberta, who dedicate part of their time to education and consultation with healthcare teams and to identify and care for potential organ donors. The role of the critical care and emergency department teams is not to increase deceased organ donation and transplantation rates; rather, it is to ensure that patients receive exceptional care, which may include transitions in goals of care and providing the opportunity for donation whenever appropriate. Given the importance placed on expert second opinions regarding prognosis for the effective implementation of donation following circulatory determination of death (DCD) in both Edmonton and Calgary protocols, providing support for physicians to deliver this service was essential.



Grande Prairie SEND Physician
Dr. Tafirenyika Madzimure

To better describe the spectrum of services provided, and to avoid misperceptions when donation specialist physicians become involved in the care of patients that may not necessarily become organ or tissue donors, the term “Specialist in End-of-Life Care, Neuroprognostication, and Donation” (SEND) was coined. In January of 2021, the SEND proposal was approved by Alberta Health and operations began that same year.

The role of SEND Physicians is multi-faceted and requires them to advocate for outstanding critical care for brain-injured patients, evidence-based neurologic prognostication, sensitive communication with patients’ families and exceptional end-of-life care. SEND Physicians also act as champions for donation whenever appropriate, helping to ensure avoidance of missed donation opportunities and continuous quality improvement in donation processes.

Give Life Alberta and the SEND Program are distinct, and as the mandate of the SEND Program transcends donation, they will remain separate. However, the programs work in close partnership at the intersection of their roles in organ and tissue donation.

Activities

Program Inception

Give Life Alberta was launched on April 1, 2023 when the amended legislation came into effect. A key component of the amended legislation was the establishment of the provincial donation program operating within AHS on behalf of the Alberta Organ and Tissue Donation Agency. The Operational Director and Medical Director were appointed on April 1, and the Program Manager on May 1. Throughout the remainder of 2023, the following actions were undertaken to establish the program.

Governance

The Provincial Donation Advisory Committee (PDAC) was established in June 2023. The committee is sponsored by the Vice President and Chief Operating Officer, Clinical Operations and the Vice President and Medical Director, Clinical Operations, Alberta Health Services. The committee is chaired by the Operational Director and Medical Director, Give Life Alberta. The 26-member committee is composed of patient and family advisors, community partners, and healthcare professionals with interest or expertise in donation. The committee provides a forum for members to share ideas and knowledge to support improvements in the provision of donation services in Alberta. The committee supports fulfillment of Section 12.3(b) of the *Human Tissue and Organ Donation Act*.

The Provincial Donation Steering Committee (PDSC) was established in December 2023. The committee is sponsored by the Vice President and Chief Operating Officer, Clinical Operations and the Vice President and Medical Director, Clinical Operations, Alberta Health Services. The committee is chaired by the Operational Director and Medical Director, Give Life Alberta. The committee provides governance of donation related activities including standardization, accreditation, quality improvement, and sustainability. The committee reviews and approves deliverables prior to reporting at provincial and local levels to AHS executive and the Minister of Health. The committee monitors national developments and maintains relationships with other provincial programs. The 30-member committee is composed of healthcare professionals with interest or expertise in organ and tissue donation, including transplantation, donation, emergency, critical care, and medical assistance in dying. Adult and pediatric specialties are represented, and the committee membership broadly covers urban and rural geographic communities in Alberta.

Human Resources

To inform the development of a staffing model, an extensive nation-wide environmental scan was undertaken. Position descriptions, skill mix, and staffing composition were determined based on leading practice and experiences from other jurisdictions. Position establishment and recruitment began in mid-2023 and continued into 2024. A full complement of program staff is anticipated to be in place by the latter half of 2024. To ensure that all components of a top-performing donation program are in place, the following positions were established.

Program Manager. The Program Manager is an experienced administrator with an extensive background in organ and tissue donation, responsible for all aspects of the strategic mandate. The Program Manager leads the creation of the strategic plan and oversees its implementation. The Program Manager establishes and maintains strong collaborative relationships with healthcare professionals, external agencies, public stakeholders and partners across the province and country to support strategies to enhance organ and tissue donation.

Senior Communications Advisor. The Senior Communications Advisor is an experienced communications expert responsible for developing and executing the branding, marketing, public awareness and community engagement strategies of Give Life Alberta. This is a strategic role that works with various stakeholders and experts throughout Alberta and nationally. The Senior Communications Advisor is also responsible for media relations and oversees the work of partner agencies.

Senior Donation Consultants. The Senior Donation Consultant is an advanced practice position dedicated to improving the quality delivery of care related to organ and tissue donation. Senior Donation Consultants have extensive backgrounds in organ and tissue donation, acting as leaders, coordinators, mentors and resources to local hospital leadership. The consultants are responsible for the development of strong working relationships between Give Life Alberta and professionals across the healthcare system.

Senior Analyst. The Senior Analyst is responsible for analytics and reporting to support system performance, transparency and accountability. The analyst oversees the validation, analysis and reporting of data for public and internal reporting. The analyst contributes to identifying opportunities for performance improvements within the donation system, supporting decision making and performance management. The analyst ensures that all information released by the program is completely and consistently accurate, provides value and enhances public knowledge and trust.

Administrative Supports. The Administrative Supports are responsible for the day-to-day operations of the Give Life Alberta provincial office, working with a strong understanding of the complex needs and priorities of the program. The positions also support the Directors, Program Manager and program staff, as well as partnering to provide administrative support to the SEND Program.

Strategic Planning

To ensure that Give Life Alberta remains focused on its core mandate and delivers on all expectations, the program uses a strategic planning model. Operating within the AHS strategic planning framework, development of the Strategic Plan was initiated in mid-2023. This included an environmental scan and engagement with a wide range of professional and public stakeholders. Several document draft-feedback-revision cycles were conducted throughout the remainder of 2023, and will continue into 2024. The first iteration of the Strategic Plan is scheduled for completion in mid-2024, following which action plans will be developed, and an annual review and revision cycle will be established.

Hospital Development

A pillar of high-performing donation programs is a robust hospital development system. “Hospital Development” refers to processes and initiatives undertaken by a donation program in partnership with hospital leadership to optimize organ and tissue donation; this is the primary focus of the Senior Donation Consultants. Components of a hospital development system generally include establishment of site-based donation committees, often referred to as Donation Resource Teams; annual action plans that include quality improvement and leading practice initiatives; professional education and promoting a culture of donation; chart audits and reporting of missed donation opportunities; regular internal and external performance reporting; awareness events, celebrations and recognition of success. To inform the development of the hospital development program, an extensive nation-wide environmental scan was undertaken.



Donation Resource Teams are comprised of local leadership, frontline staff and physicians to oversee donation activities at the site. Senior Donation Consultants will co-chair the committees and serve as leaders and resources for all site initiatives. Give Life Alberta is in the process of working with local leadership to establish Donation Resource Teams. The early priorities of the teams will be to review key performance indicators and perform SWOT (Strength, Weakness, Opportunities, Threats) analyses which will inform the development of site action plans. Initiatives flowing from the site action plans will generally follow the PDSA (Plan, Do, Study, Act) model in a quality improvement cycle. Initiatives will be site-specific and will evolve over time as the system continues to mature.



Heather Cohrs
Senior Donation
Consultant



Corinne Marceau
Senior Donation
Consultant



Kerry Holliday
Senior Donation
Consultant

Donation Resource Teams will develop site-specific education plans with a heavy initial education focus on tissue donation. To support this, Give Life Alberta developed an online education module for AHS staff and physicians. Give Life Alberta is also developing instructor-led education to be delivered throughout the organization as determined by the Donation Resource Teams. Give Life Alberta will continue to optimize content and materials, leveraging leading practice and public domain resources.

A significant change in the new legislation is Mandatory Referral, which requires that when a person dies or their death is imminent, the medical practitioner making the determination of death must refer that individual to the donation program unless specific ineligibility criteria are present. To coincide with Mandatory Referral legislation coming into force, Give Life Alberta developed and disseminated organ and tissue donation referral algorithms throughout AHS. Give Life Alberta continues to utilize these algorithms as key learning tools and standard operating procedures.

Public Education and Awareness

Through a competitive proposal process, Give Life Alberta contracted a local advertising agency to develop the program name, brand, web page and advertising campaign. Work began in late 2023, and is scheduled for completion and launch in April 2024 to coincide with National Organ and Tissue Donation Awareness Week.

Give Life Alberta is developing a long-term public awareness and education strategy, which will be a living document as goals are achieved and the landscape evolves.

Give Life Alberta will adopt a mechanism to assess public trust and patient and family satisfaction. Through consultation with AHS Community Engagement, and under the guidance of PDAC which includes patient and family advisors, a formal mechanism to gauge public trust and patient and family satisfaction on an ongoing basis will be implemented.

Give Life Alberta will develop a strategy to adapt education to various cultural communities. This will include determination of which communities will benefit from adapted materials, and a plan to develop and socialize education in consultation with these communities. Give Life Alberta's public awareness strategies will identify the Alberta Organ and Tissue Donation Registry as the primary mechanism for documenting wishes related to donation. Give Life Alberta will work with Alberta Health to trend registrations over time. While it is not possible to attribute growth in registrations to any individual initiative, milestones will be noted (e.g., new advertising campaigns) and assessed for impact on registrations. Targets will be established and monitored.

Give Life Alberta joined the Canadian Blood Services Public Education and Awareness Committee in 2023, and continues to collaborate with other provincial jurisdictions to enhance alignment, leveraging of synergies and sharing of leading practices. Give Life Alberta collaborates with the Alberta Transplant Institute's Public Advocacy Committee to enhance community engagement, stay connected to the work of community partners (e.g., Alberta ORGANization Group, Kidney Foundation of Canada) and to support public advocates with messaging that aligns with our public education and awareness strategy.



Shawnee Brave Rock saved five lives with her organ donations in the spring of 2023.

Analytics and Reporting

Give Life Alberta will support system performance through monitoring and reporting key performance indicators. The Annual Report will be the primary mechanism for public reporting and accountability. Public reporting of performance metrics will be incorporated into future iterations of the Give Life Alberta web page. Site-specific performance reports will be provided to AHS executive and site leadership on a regular basis.

Medical record review for missed organ donation opportunities is a joint initiative between the SEND Program and Give Life Alberta. Every patient who dies in a way that may potentially allow for organ donation is audited by a Senior Donation Consultant and a SEND Physician to ensure that the option of organ donation is offered where appropriate. Close to 400 charts are reviewed annually. Case reports of missed opportunities and summative reports are provided to physicians and leadership.

Give Life Alberta has established a dashboard utilizing clinical data to determine tissue donation potential and other key performance indicators, as potential tissue donors are too numerous for manual chart reviews. Reporting from the dashboard will be distributed with the ongoing organ donation reports.

The analytics program will also support research, innovation and quality improvement through in-kind contributions to quality and research initiatives.

Living Donation

Living donation is complex and substantially different from deceased donation in terms of clinical pathways, patient care, public awareness and education, and quality improvement. Give Life Alberta is currently determining the optimal mechanisms to carry out its mandate related to living donation.

Information Systems

iTransplant®. Give Life Alberta, in partnership with the Canadian Institute for Health Information and Canada Health Infoway, is implementing the iTransplant deceased donor management system, an electronic medical record from InVita Healthcare Technologies that facilitates the organ donation process. Through enhanced efficiency and safety, iTransplant will support the donation programs in managing the increased activity that will result from the work of Give Life Alberta. The system will also support improved analytics and reporting. This initiative is funded by Canada Health Infoway within the mandate of the federal Organ Donation and Transplantation Collaborative.

Closing

We are proud of the accomplishments of Give Life Alberta in 2023; however, our work toward creating a culture of donation in our province is just beginning. As our program evolves, we aim to improve public awareness to the point where families will discuss their donation decisions around the dinner table, long before they are ever asked to consent to a loved one's donation. We will continue to support patients, families and healthcare providers in high-quality donation-related care, ensuring inclusion and cultural safety. We also strive to optimize both donation rates and system performance through ongoing assessments, provincial harmonization and promoting practices which minimize missed donation opportunities.

Our goal is that all Albertans can expect the opportunity to discuss organ and tissue donation as part of their care journey. After a transformative 2023, Give Life Alberta looks forward to an impactful 2024.

Contact Us

For more information, please contact:

Give Life Alberta

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 **GiveLifeAlberta.ca**

Appendix I: Data Definitions

Eligible Deceased Organ Donors: Patients who died in an emergency department or intensive care unit where death was related to recent neurologic injury, were mechanically ventilated within 12 hours of death, and were determined eligible for donation through the SEND Program medical record review.

Referred Deceased Organ Donors: Eligible Deceased Organ Donors who were referred to the organ donation program.

Actual Deceased Organ Donors: Consented donors from whom at least one organ was recovered with the intention to transplant.

Deceased Donors per Million Population (Organ): Actual Deceased Organ Donors divided by the total population of Alberta measured in millions. Population estimates are obtained from the Statistics Canada January 1 data for each year.

Consent Rate (Organ): The number of consents obtained for organ donation divided by the number of Referred Deceased Organ Donors whose family/substitute decision-maker was approached for organ donation, or whose family/substitute decision-maker initiated an organ donation discussion with a healthcare professional.

Living Organ Donors: A consented living organ donor from whom an organ was recovered with the intention to transplant.

Organ Transplants: The number of transplant procedures performed. Multi-organ transplants were counted as one transplant (e.g., kidney/pancreas, multivisceral).

Referred Deceased Tissue Donors: Patients that were referred to the tissue donation program as potential donors.

(Note: It is not possible to quantify the number of Eligible Deceased Tissue Donors, as the quantity of deaths to review is prohibitively large and deaths occur in a broad range of locations, many of which occur outside of an AHS facility.)

Actual Deceased Tissue Donors: Consented donors from whom at least one tissue was recovered with the intention to transplant.

Deceased Donors per Million Population (Tissue): Actual Deceased Tissue Donors divided by the total population of Alberta measured in millions. Population estimates are obtained from the Statistics Canada January 1 data for each year.

Consent Rate (Tissue): The number of consents obtained for tissue donation divided by the number of Referred Deceased Tissue Donors whose family/substitute decision-maker was approached for tissue donation, or whose family/substitute decision-maker initiated a tissue donation discussion with a healthcare professional. Give Life Alberta is currently unable to report this metric; a gap which will be addressed.

Living Tissue Donors: A consented living tissue donor from whom a tissue was recovered with the intention to transplant. Live tissue donations in Alberta are limited to surgical byproducts (e.g., femoral heads, placentas).

Allografts Distributed: Tissue allografts distributed with the intention to transplant.

Tissue: In all cases, tissue refers to both ocular and non-ocular tissues.