

# SAVING LIVES THROUGH NO MISSED ORGAN & TISSUE DONOR OPPORTUNITIES

The Kidney Foundation is committed to improving Alberta's organ and tissue donation and transplantation rates.

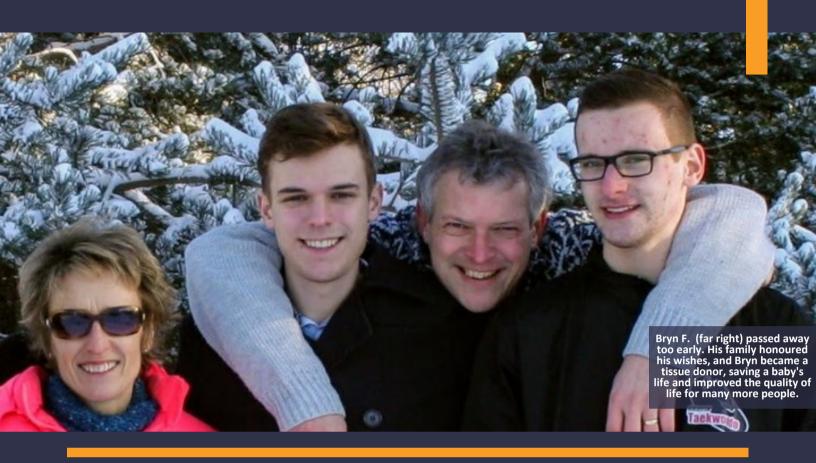
BECAUSE PEOPLE ARE NEEDLESSLY DYING

**WE MUST DO BETTER** 

YOUR FAMILY, FRIENDS, NEIGHBOURS, AND THOSE IN THE TRANSPLANT COMMUNITY NEED YOU TO STAND UP, GET LOUD, AND FIGHT TO INCREASE ALBERTA'S TRANSPLANT RATES

On behalf of the hundreds of Albertans waiting for an organ transplant or tissue donation, in honour of the thousands who have died in need of an organ transplant, and for the hundreds of thousands of Albertans who have selflessly registered as organ and tissue donors, we must ensure that every Albertan's decision to donate is honoured and respected.

MoreTransplants.ca



I honestly can't imagine why anyone would not want to donate .... and I truly hope that no family will live a lifetime of regret at withholding consent ... and living with 'nothing'...

- DONOR FAMILY

## OUR GOALS

- Saving lives through no missed organ & tissue donor opportunities.
- For Albertans' wishes to donate their organs & tissue to be respected and honoured.
- For Alberta to become a leader in deceased organ & tissue donation and transplantation.



## WHO ARE WE FIGHTING FOR?



### ALBERTANS ON AN ORGAN TRANSPLANT WAIT LIST



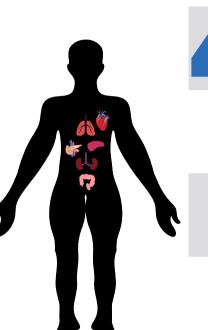
THOUSANDS OF OTHERS IN NEED OF A TRANSPLANT, BUT NOT CURRENTLY ELIGIBLE.

#### **ALBERTANS**

NEED MORE

#### **ORGAN & TISSUE DONATIONS**

TO SAVE LIVES AND SAVE MONEY NOW!





PATIENTS ON A TRANSPLANT WAITLIST. THIS IS THE FOURTH HIGHEST IN CANADA, BEHIND ONTARIO, BRITISH COLOMBIA, AND QUEBEC.



WAIT TIME FOR A
KIDNEY TRANSPLANT
FROM A DECEASED DONOR IS UP TO



TH M

MOST EXPENSIVE TREATMENT



IS FOR CHRONIC KIDNEY FAILURE (AHS, 2017)

#### COVID IMPACT HAS ONLY INTENSIFIED THE NEED.



EARLY RESEARCH INDICATES THAT LONGER TERM ORGAN DAMAGE IS EMERGING AS AN EFFECT OF THIS DEVASTATING PANDEMIC.

### **ALBERTA CAN BE A LEADER**

Minister LaGrange, it is within your authority as the Minister of Health to ensure Albertans have improved access to world-class health care when and where they need it. Within OTDT, I request you implement the following:

- Funding: Aligned with the Alberta Organization Group's (AOG) analysis, a commitment of new money, \$25 30 million, over the next ten years to support policy and operational change required after the passing of Bill 205.
- Leadership: An integrated pan-provincial system that integrates HOPE and SAODTP with a transparent, full-time, accountable, senior executive Champion and Leader.



Solving Alberta's organ and tissue donation & transplantation crisis requires government leadership and government-led policy solutions.

### Because...

- Transplantation is the most clinically effective treatment for organ failure.
- Transplantation is the most costeffective treatment for organ failure.



Through continuous work with many stakeholders, including patients, families, and donors, we started or achieved the following steps between 2021-23

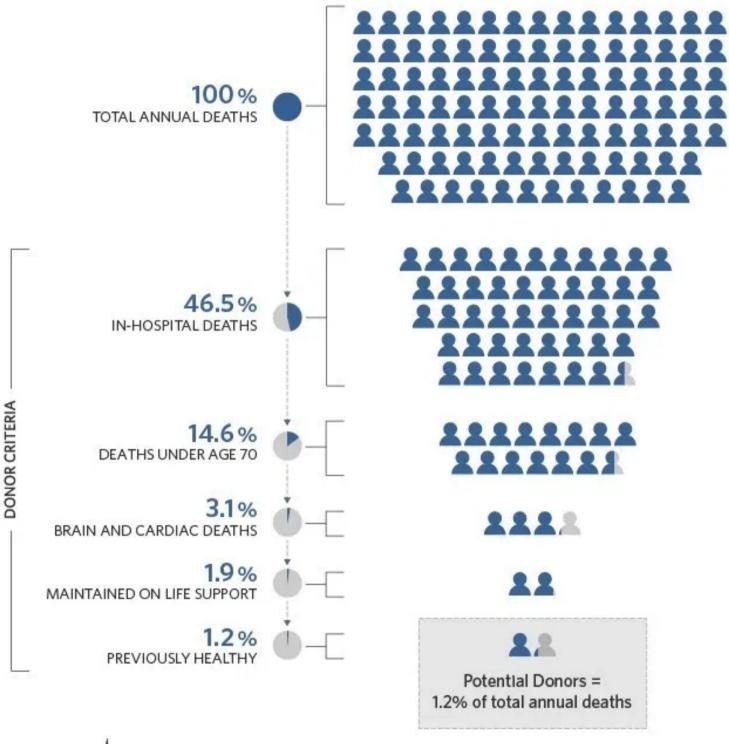
Legislation Amendment
(replace Mandatory
Consideration with
Mandatory Referral) and
implementation of provisions
of the Human Tissue & Organ
Donation Amendment Act.

Establish specifically trained
Donation Teams (specialized
in donor identification, donor
referral and donor
management

Implement continuous and Real-Time Audits, as an essential best practice in urban and large rural centres

Ensure a user-friendly donor registration system

### Potential Deceased Donors as a Proportion of Total Annual Deaths





### Presumed Consent & Registries: A Word of Caution.

- Advocates of presumed consent tend to count all members of the general population as potential donors. However, this is misleading because few individuals will ever be in the situation of being considered for organ donation upon their death (~1-2%).
- Proponents of donor registries (databases containing the names of individuals who wish to donate their organs after death) also suggest databases better reflect the donor pool.
- As with the general population, this is not strictly true, because the number of individuals
  who ultimately become available as possible donors ("potential donors") is a small
  fraction of those who may be interested in becoming a donor ("intended donors").
- That said, online registries and registering as an organ donor IS a great way to start the conversation with your family and friends.

### PRESUMED CONSENT IS NOT A SILVER BULLET. WE NEED MORE.

- Albertans who are 18+ can register as an organ donor via the online Organ and Tissue
   Donation Registry, at a registry office, or by signing the back of their healthcare card.
- However, we know not everyone is asked about their intentions to donate at registries, despite legislation mandating this.
- There isn't enough public education. Often, individuals are first introduced to the conversation at this point of contact and quite frankly, this doesn't allow individuals to make an informed decision.
- Registering your intentions to Alberta's online registry does not ensure your wishes will be honoured.
- Even if you have followed those steps, organ donation will only proceed if consent is received from the family. If there is disagreement among the family, donation will not proceed.
- In other words, REGISTERING YOUR WISHES IS NOT ENOUGH!!

A culture of organ and tissue donation and transplantation needs to be achieved in Alberta to impact lives.

Presumed consent is not the solution in Alberta.

In the Photo: Logan Boulet

On April 7, 2018, Humboldt Broncos defenceman Logan Boulet succumbed to his injuries. His family honoured his wishes and donated his organs so that six lives could live on.

#### START THE CONVERSATION

Talking about organ & tissue donation can be difficult, but with the right tools, you can start the conversation.

- 1. Learn about the organ & tissue donation process. Visit MoreTransplants.ca & contact your local Kidney Foundation office for additional information.
- 2. Make a decision that works best for you. Share your wishes about what you want to happen at the end of your life with your loved ones. Discuss why you've made the decision.
- 3. Be LOUD and PROUD! Let everyone know you've registered as an organ & tissue donor and why you made this lifesaving choice.
- 3. Talk to your family and friends about organ & tissue donation. Challenge them to do the same.

### SHARE YOUR STORY

Why do you care about organ & tissue donation, and transplantation? You can help save lives and fight for change by sharing your story.

- 1. Share your story on social media. You can post a photo or video to show Albertans the faces of organ & tissue donation.
- 2. Inspire people to take action (join the campaign, register to be a donor, re-share your story).
- 3. Tag us & use #KidneyFoundationNABT #MoreTransplants #NoMissedDonorOpportunities when you post online.
- 4. Tag the Premier of Alberta, the Minister of Health, the Leader of the Official Opposition, and your MLA in your post!
- 5. Contact us at Info.NABT@Kidney.ca so we can share your story on our social media channels and MoreTransplants.ca

Whether you or a loved one is on a transplant wait list, you are a living organ donor, or are a registered organ or tissue donor, your voice matters.

### CONTACT YOUR MLA

You will not be met with resistance. Both Government and Opposition Members have a strong history of believing in organ & tissue donation and supporting changes to improve Alberta's organ & tissue donation system.

- 1. Contact your MLA and ask for a meeting. Share why you believe in organ & tissue donation, share your story, and ask your MLA to urge the government to implement policy changes.
- 2. Write a letter to your MLA! Pre-written constituency letters are located at MoreTransplants.ca. Download, personalize, sign, mail (or email) your letter.
- 4. Use social media to engage your MLA. Visit MoreTransplants.ca for resources and contact us at Info@MoreTransplants.ca for further support.
- 5. Always tag the Premier, the Minister of Health, the Leader of the Official Opposition, and Your email on all social media posts.



The Honourable Adriana LaGrange Minister of Health Office of the Minister of Health 423 Legislature Building 10800 – 97 Avenue

## DOWNLOAD OUR SUPPORT LETTER ON MORETRANSPLANTS.CA AND WRITE THE MINISTER OF HEALTH AND YOUR MLA

organ and tissue donation and transplantation (OTDT). I am calling upon the government to continue its leadership and invest in establishing an OTDT system that unequivocally prioritizes organ and tissue donation, ultimately improving the lives of those waiting on transplant lists.

Alberta Government has the opportunity to become this leader in OTDT and directly improve the lives of thousands waiting for a transplant and a life-altering tissue donation, honour all who have died waiting for a transplant, and recognize hundreds of thousands of Albertans registered as organ donors.

Minister LaGrange, it is within your authority as the Minister of Health to ensure Albertans have improved access to world-class health care when and where they need it. Within OTDT, I request you implement the following:

- Funding: Aligned with the Alberta Organization Group's (AOG) analysis, a commitment of new money, \$25 –
  30 million, over the next ten years to support policy and operational change required after the passing of Bill
  205
- Leadership: An integrated pan-provincial system that integrates HOPE and SAODTP with a transparent, fulltime, accountable, senior executive champion and leader.

Alberta's deceased donation rates have been lower compared to that in other higher performing provinces over the past fifteen years or more (British Columbia, Ontario, Quebec, and Nova Scotia). Rate have increased recently; however, this is partly due to the devastating result of the opioid crisis. Other provinces have invested in a single integrated provincial agency responsible for the effective administration and coordination of organ and tissue donation and transplantation services. It is time and the opportunity for Alberta to be transformational.

Under our existing system, Alberta cannot modernize effectively due to its fragmented dual structure (North and South). This means that every day, thousands of Albertans are needlessly suffering, and many die. This is unacceptable. Minister LaGrange, these steps are needed to embrace innovative, sustainable, comprehensive, and lifesaving change to Alberta's organ & tissue donation system.

Organ donation is the ultimate gift of life, but more is needed to ensure no missed donor opportunities. Why? Because one donor can save the lives of up to eight people and improve the quality of life of another 75. Our current system has failed too many. I am calling upon the government to establish an OTDT system that unequivocally prioritizes organ and tissue donation, ultimately improving the lives of those waiting on transplant lists.

Again, this can be achieved by investing \$25 - 30 million. At a time when fiscal responsibility is imperative, the new Alberta deceased donation program will be self-funding after six years (\$15 million), and the remaining funds will be used for continuous improvement and demand. This investment will improve the lives of up to 2700 patients and save Alberta Health and Alberta Health Services up to \$400 million over ten years.

It is time to commit new money, \$25-\$30 million, over the next ten years to modernize a fragmented system and ensure Albertans are not needlessly dying. I urge you to include this funding in the 2024-2025 budget or earlier.



# 486 ALBERTANS ARE WAITING FOR A DONOR ORGAN

# THOUSANDS MORE NEED A TRANSPLANT BUT ARE INELIGIBLE



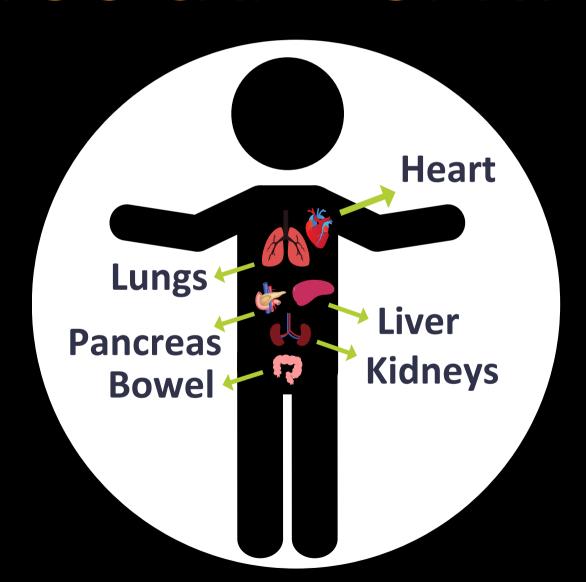




Bringing liver research to life Donner vie à la recherche sur le foie

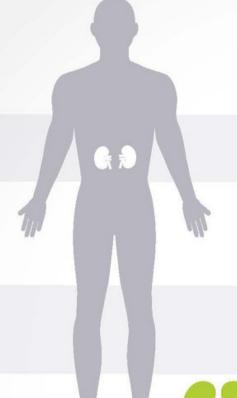
BREATHE the lung association

### ORGANS YOU CAN DONATE



REGISTER. TELL YOUR FAMILY.
MORETRANSPLANTS.CA







74% OF CANADIANS WAITING FOR AN ORGAN TRANSPLANT ARE WAITING FOR A KIDNEY.

THE MEDIAN WAIT TIME FOR A KIDNEY TRANSPLANT FROM A DECEASED DONOR IS OVER



OF ADULT KIDNEY TRANSPLANTS ARE MADE POSSIBLE BY LIVING DONORS



**51%** OF ALL ADULT LIVING KIDNEY DONORS ARE NOT A BLOOD RELATIVE OF THE RECIPIENT.





THE KIDNEY PAIRED DONATION PROGRAM HAS MADE 1,000 TRANSPLANT POSSIBLE SINCE 2008.2

YOU CAN BE A PART OF THE SOLUTION.

Consider living organ donation.

Join the Kidney Paired Donation Program Registry. Learn more: kidney.ca/Organ-Donor-Programs

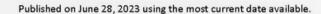
Register your intention to donate your organs through your provincial donor registry. Find out more: kidney.ca/Register

Speak to your family and loved ones to make sure they know and honour your wishes.

#### LEARN MORE ABOUT KIDNEY HEALTH AND ORGAN DONATION AT KIDNEY.CA

Important Note: The COVID-19 pandemic has placed unprecedented burdens on Canadian healthcare systems in 2020. Priorities were reassessed and resources reassigned, resulting in an unfortunate decrease in the number of kidney transplants performed.

Sources Canadian Institute for Health Information. Summary statistics on organ transplants, wait-lists and donors [release summary]. https://www.cihi.ca/en/summary-statistics-on-organ-transplants-wait-lists-and-donors 1. Canadian Institute for Health Information. Organ replacement in Canadia. CORR annual statistics [product release]. https://www.cihi.ca/en/organ-replacement-in-canada-corr-annual-statistics 2. Canadian Blood Services. Kichey Paired Donation Program. https://profession.aleducation.blood.ca/en/organ-sand-tissue/programs-and-services/kichey-paired-donation-kpd-program





### THANK YOU.

## YOUR VOICE & YOUR ACTIONS CAN SAVE LIVES.



Campaign Supported by:



