

### SAVING LIVES THROUGH NO MISSED ORGAN & TISSUE DONOR OPPORTUNITIES

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

#### **BECAUSE PEOPLE ARE NEEDLESSLY DYING**

Today, Alberta's deceased organ donation rate lags behind other provinces, the Canadian average, and is well below other developed countries and jurisdictions.

#### 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.



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 cost-effective treatment for organ failure.
- With no changes, Alberta's combined kidney dialysis and all organ transplant budget cost will be approximately \$3.5 \$4.0 billion (in constant \$ terms). Over the same 10 years, Alberta's Health budget is expected to be approx. \$220 billion (in constant \$ terms).

### OUR ASK

The path forward requires a resource re-allocation commitment of \*\$15 million dollars (over 3 years) to implement evidence-based policy changes which will save money and save lives

### The Path

- 1. Establishment of a pan-Alberta System with dedicated full-time leadership, efficient structure, dedicated infrastructure with accountability.
- 2. Legislation Amendment (replace Mandatory Consideration with Mandatory Referral) and implementation of provisions of the Human Tissue & Organ Donation Amendment Act.
- 3. Create a Culture of Organ & Tissue Donation to improve public awareness of the need and benefits of organ & tissue donation, and transplantation.
- 4. Provide dedicated donation and transplant facilities consistent with best-performing jurisdictions.



#### **STEPS ACHIEVED!!**

#### **Donation Teams**

Donation Teams (specialized in donor identification, donor referral and donor management)

#### **Donor Audit**

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

#### **Registration System**

Ensure a user-friendly donor registration system

## The Results: Saving Lives Saving Money

1800

Additional Lives
Saved at the end
of Year 10

**600** 

Fewer Albertans on Dialysis at the of Year 10

\$1 Billion

> Macro-Economic Benefit at the end of Year 10

At a time when fiscal responsibility is imperative, the ~\$15 million reallocation will pay for itself within 3-5 years.

This includes a CASH SAVINGS of \$175 million



### Aspirational End Results

3000

Additional Lives
Saved at the end
of Year 10

900

Fewer Albertans on Dialysis at the end of Year 10

\$1.5+ Billion

Macro-Economic Benefit at the end of Year 10

The ~\$15 million reallocation will pay for itself within 2-3 years as best-practices push ahead faster.

This includes a CASH SAVINGS of \$375 million



#### **Presumed Consent & Registries**

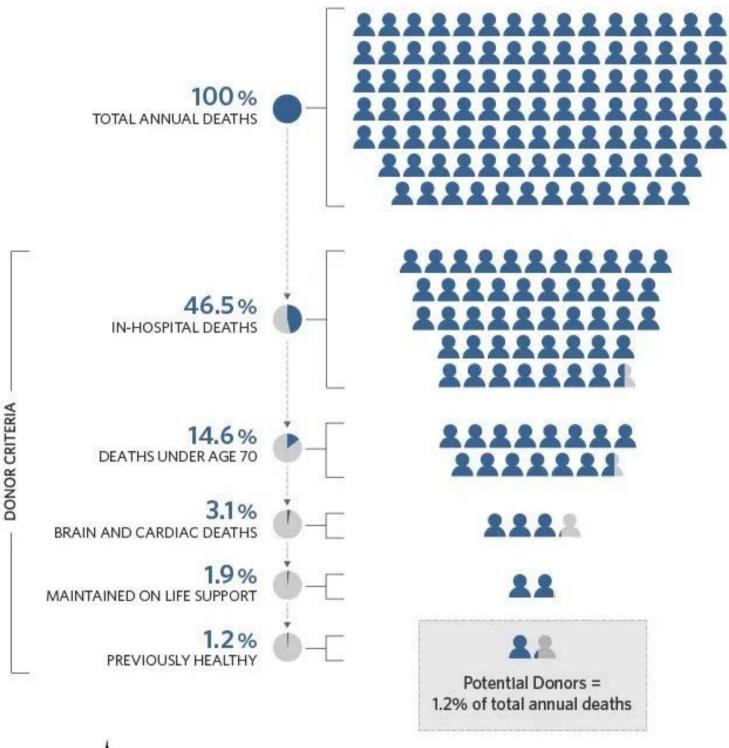
- Advocates of presumed consent tend to count all members of the general population as potential donors. However, this is misleading because few individuals will ever be in the situation of being considered for organ donation upon their death (~1-2%).
- Proponents of donor registries (databases containing 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.

#### A WORD OF CAUTION

- 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 are being 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!!

Note: Both presumed consent and online registries can be useful tools to <u>compliment</u> organ donation and transplant policy only <u>AFTER</u> Alberta's procurement system has implemented the above policy changes.

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





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@MoreTransplants.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.
- 3. Sign our Petition urging the Legislative Assembly to take action, to save lives, and save money.
- 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 Tyler Shandro Minister of Health Office of the Minister of Health 423 Legislature Building 10800 – 97 Avenue Edmonton, Alberta TSK 2B6



#### RE: SAVING LIVES THROUGH NO MISSED DONOR OPPORTUNITIES.

I am writing you today on behalf of the thousands of Albertans waiting for an organ transplant, for those waiting for a life altering tissue donation, in honour of the thousands who have died while in need of an organ transplant, and in recognition of the hundreds of thousands of Albertans who have selflessly registered as organ donors.

Every day, thousands of Albertans are needlessly suffering, and many die because of Alberta's inaction on organ donation. This is unacceptable. As a member of Alberta's transplant community, I've seen how organ failure and organ donation impacts the lives of our loved ones. Organ donation is the ultimate gift of life, but more is needed to ensure there are 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. Frankly, I need the government to implement an organ donation and transplant system that successfully and purposefully makes organ donation a priority, so the lives of those on a transplant waitlist can be saved.

Minister Shandro, I am asking you to implement the following changes to ensure there are no missed donor opportunities. These changes will save lives and will save money.

#### OUR IMMEDIATE ASK:

- Establishment of a pan-Alberta system with dedicated full-time leadership, efficient structure, and dedicated infrastructure with accountability
- Legislation Amendment (replace Mandatory Consideration with Mandatory Referral) and implementation of provisions of the Human Tissue & Organ Donation Amendment Act
- Create a Culture of Organ & Tissue Donation improve public awareness of the need and benefits of organ
  donation (i.e. one donor can save up to 8 lives through organ donation & improve quality of life for 75 others
  through tissue donation)
- Provide dedicated donation and transplant facilities (prioritized OR access) consistent with best-performing jurisdictions

#### OUR SINCERE THANKS FOR ADDRESSING THE FOLLOWING CRITICAL STEPS ACHIEVED IN 2021:

- 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.

Minister Shandro, these are the steps needed to embrace innovative, sustainable, comprehensive, and lifesaving change to Alberta's organ & tissue procurement system. These policy choices are attainable, evidence-based, and can be implemented in Alberta. Anything less is a band-aid solution that will provide minimal improvement to a system that is already overstretched. You can be the leader who does not accept mediocrity, but rather, has the vision to strive for a greater future for all Albertans.

These policy changes can be achieved by re-allocating ~\$15 million over the next 3-5 years. To be clear, this is a reallocation of existing funds. At a time when fiscal responsibility is imperative, the <u>~\$15 million will pay for itself within 3-5 years.</u>¹

Reference AOG's Deceased Organ Donation and Transplantation in Alberta: Patient Outcomes & Economic Case Document, June 2020. (Working Document)





#### The lives impacted are as follows:

- A decrease of 140 dialysis patients at the end of year 5 (and a reduction of 600 dialysis patients at the end of year 10)
- o 400 additional lives saved at the end of year 5 (and 1800 additional lives saved at the end of year 10)

#### **CONTACT YOUR MLA**

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With no change in the system over the next ten years, Alberta's combined kidney dialysis and all organ transplantation budget is forecast to be \$3.5-\$4 Billion (in constant \$ terms). Over the same 10 years, Alberta's Health budget is expected to be approximately \$220 billion (in constant \$ terms).

Since the passing of Bill 207, the Human Tissue and Organ Donation Amendment Act in 2013, the Government of Alberta has yet to implement all the legislative changes outlined in the Bill. The time to act is now, especially in light of your comment on January 28, 2021 informing Albertans that "Ultimately, our goal is to improve donations rates and save every life possible."

In our present system, my registered intention to become an organ and tissue donor is not being respected and honoured.

Currently, Alberta's deceased organ donation rate lags other provinces, the Canadian average, and is well below many other developed countries. The fact is many Albertan's lives are at stake. We urge you, indeed we beg you, to take the issue of deceased organ donation seriously and act by urging the Government of Alberta to implement the policy changes outlined above.

Your colleague, MLA R.J. Sigurdson, has committed to using this evidence-based strategy as the framework for his upcoming Private Members' Bill (205). Given that many Private Members' Bills do not pass due to time constraints within the legislative process, I urge you to show leadership and convert Bill 205 into a government bill. There is precedent. On May 13, 2013, Government House Leader Dave Hancock moved that Bill 207, The Human Tissue and Organ Donation Amendment Act, 2013, be moved to Government Bill and Orders on the Order Paper because "It's a bill which I think there's a general agreement on that it should move forward, and we want to get it moving forward so that we can deal with this very important topic."

Donation is a non-partisan issue, and I urge you to make Bill 205 into a Government Bill. Anything less will be a stop-gap that will continue the endless suffering and needless deaths of those waiting for a transplant. Anything less will be a stop-gap that will continue the endless suffering and needless deaths of those waiting for a transplant.

Minister Shandro, thank you for taking the time to read my letter. It is time Alberta becomes a leader in deceased organ and tissue donation and transplantation, and that the wishes of all Albertans to donate are respected and honoured.

Sincerely,

#### SIGN THE PETITION

To the Legislative Assembly of Alberta, in Legislature Assembled:

We, the undersigned residents of Alberta, petition the Legislative Assembly to urge the Government of Alberta to take all necessary steps to achieve the following:

- 1) Implement evidence-based solutions to address current gaps in Alberta's organ & tissue donation, and transplantation procurement system, and
- 2) Develop policies and legislative initiatives to address current and future priorities with respect to organ donation and transplantation, including

#### **OUR IMMEDIATE ASK**

- 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.

#### **NEXT STEPS**

- Introduction of a Bill to amend to current legislation to replace the system of mandatory consideration of donors with a system of mandatory referral of donors by doctors, and to implement the provisions found in Bill 205, Human Tissue and Organ Donation (Presumed Consent) Amendment Act, 2019;
- Creation a culture of organ & tissue donation by improving public awareness of the need and benefits of organ
  donations (i.e. one donor can save up to 8 lives through organ Donation and improve quality of life for 75 others
  through tissue donation);
- Establishment of a pan-Alberta donation and transplantation system with dedicated full-time leadership, an efficient structure and the infrastructure required to be effective and accountable;
- Establishment of dedicated donation and transplant facilities, including prioritized operating room access in hospitals, consistent with best-performing jurisdictions;
- Development of a user-friendly donor registration system to facilitate donations.

Note: The name and addresses of the persons who sign this petition may be made available to the public if the petition is in proper form to be presented in the Legislative Assembly of Alberta

#### SAMPLE SOCIAL MEDIA POSTS

#### **Organ Donation**

- Did you know 645 Albertans are waiting for a life-saving organ transplant? That doesn't count those too sick to be on the wait list.
   Learn how you can support organ donation at MoreTransplants.ca
- Have you talked to your family about organ & tissue donation? Let your family know your end-of-life decision.
- Have five minutes? Talk to your family about organ & tissue donation and decide what is best for you so your wishes are respected & honoured.
- One person can save up to 8 lives! Register your decision for #OrganDonation at MyHealth.Alberta.ca.
- One tissue donor can impact up to 75 lives! Register your decision for #TissueDonation at MyHealth.Alberta.ca
- One conversation could save a life. Talk to your loved ones about organ & tissue donation.
- Organ & tissue donation saves lives. It's that simple. Register to be an organ & tissue donor today and let your family know your decision.
- Learn more about the organ & tissue donation process and the lifesaving impact it leaves at MoreTransplants.ca
- Stand up, FIGHT, and let's get LOUD for organ & tissue donation. Join me in the fight to increase Alberta's transplant rates. Learn more at MoreTransplants.ca

#### **SAMPLE FACEBOOK POSTS**

#### No Missed Donor Opportunities Campaign

ALWAYS Tag @KenneyJasont @TylerSShandro @RachelNotey @[YOUR MLA]

Use the hashtags #NoMissedDonors #MoreTransplants

ALWAYS direct others to MoreTransplants.ca

- It's time to do better. The Alberta Government must show leadership and action by improving Alberta's organ & tissue donation, and transplantation system. Learn how at MoreTransplants.ca
- Alberta's deceased organ donation rate lags behind other provinces, the Canadian average, and is well below many other developed countries. It's time to ensure every Albertan's decision to donate is honoured and respected.
- Show your leadership and improve Alberta's organ donation & transplant system. Help save the lives of 1800 Albertans, realize a macro-economic benefit of \$1 billion dollars (includes cash savings of \$175 million), and end the needless suffering of Albertans on dialysis and waiting for a transplant.
- Albertans deserve an organ & tissue donation, and transplant system that honours our wishes to donate. It's time to do the work and implement an evidence-based system. It's time to save lives and save money.
- Registering your wishes to be an organ & tissue donor is not enough! It's time for real action to fix Alberta's organ & tissue donation, and transplant system.
- Every day, Albertans are needlessly dying while waiting for a transplant.
- Every day, Albertans are needlessly suffering waiting for a transplant that may never come.
- Every day, Albertans are needlessly suffering while waiting for a tissue donation that may never come.

#### **SAMPLE TWITTER POSTS**

#### No Missed Donor Opportunities Campaign

ALWAYS Tag @JKenney @Shandro @RachelNotey @dryiu\_Verna @[YOUR MLA]

Use the hastags #NoMissedDonors #MoreTransplants

ALWAYS direct others to MoreTransplants.ca

- It's time the AB Government shows leadership & action by improving Alberta's organ & tissue donation, and transplantation system.
- Alberta's deceased organ donation rate lags BC, MB, ON, QC, NS, and the Canadian average. It's time the AB Government implement the key components of a high functioning system.
- Your leadership will help save the lives of 1800 Albertans, realize a macro-economic benefit of \$1 billion dollars (includes cash savings of \$175 million), and end the needless suffering of Albertans on dialysis and waiting for a transplant.
- Albertans deserve an organ & tissue donation, and transplant system that honours our wishes to donate. It's time to save lives and save money.
- Registering your wishes to be an organ & tissue donor is not enough! It's time for real action to fix Alberta's organ & tissue donation, and transplant system.
- Every day, Albertans are needlessly dying while waiting for a transplant.
- Every day, Albertans are needlessly suffering waiting for a transplant that may never come.
- Every day, Albertans are needlessly suffering while waiting for a tissue donation that may never come.
- 654 Albertans are on a transplant waitlist. THOUSANDS more are in need of a transplant. Show your leadership and fix our system so there are no missed donor opportunities.
- ~600 Albertans are waiting for a transplant each year. Many will never receive a transplant because of the limited number of organs for transplant.
- Organ & tissue donation is the gift of life. It's time the wishes of those who made the
  decision to donate are respected and honoured.



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#### neople and things No Missed Donor Opportunities Campaign

ALWAYS Tag @JKenney @TylerShandro @RachelNotleyAB @[YOUR MLA] Use the hastags #NoMissedDonors #MoreTransplants ALWAYS direct others to MoreTransplants.ca

- Only 1% 2% of deaths may lead to organ donation. It's time the Alberta Government shows leadership & improves Alberta's organ & tissue donation, and transplantation system so there are no missed donor opportunities.
- Alberta's deceased organ donation rate lags BC, MB, ON, QC, NS, and the Canadian average. It's time the AB Government implement the key components of a high functioning system.
- Your leadership will help save the lives of 1800 Albertans, realize a macro-economic benefit of \$1 billion dollars (includes cash savings of \$175 million), and end the needless suffering of Albertans on dialysis and waiting for a transplant.
- Albertans deserve an organ & tissue donation, and transplant system that honours our wishes to donate. It's time to save lives and save money.
- Registering your wishes to be an organ & tissue donor is not enough! It's time for real action to fix Alberta's organ & tissue donation, transplant system.
- Every day, Albertans are needlessly dying while waiting for a transplant.
- Every day, Albertans are needlessly suffering waiting for a transplant that may never come.
- Every day, Albertans are needlessly suffering while waiting for a tissue donation that may never come.
- 654 Albertans are on a transplant wait list. THOUSANDS more are in need of a transplant. Show your leadership and fix our system so there are no missed donor opportunities.
- Organ & tissue donation is the gift of life. It's time the wishes of those who made the decision to donate are respected and honoured.



## ONE ORGAN DONOR CAN SAVE UP TO 8 LIVES AND ENHANCE 75 LIVES

No Missed Donor Opportunities MoreTransplants.ca



#### SAMPLE SOCIAL MEDIA IMAGES

#### Why is Organ Donation Important?

- Transplantation is the most clinically effective treatment for organ failure.
- Transplantation is the most cost effective treatment for kidney failure.
- Organ donors and transplantation SAVE lives. Between 2015 - 2018, 441 Albertans died or withdrew from a transplant wait list.











#### Every day...

your family, friends and neighbours are needlessly dying while waiting for an organ transplant



No Missed Donor Opportunities MoreTransplants.ca

#### SAMPLE SOCIAL MEDIA IMAGES





#### Every day...

your family, friends and neighbours are needlessly suffering on dialysis while waiting for a transplant that may never come





#### On Jan. 28, 2021

The Minister of Health Tyler Sandro Said:

## "Ultimately, our goal is to improve donation rates and save every life possible."

No Missed Donor Opportunities MoreTransplants.ca

#### SAMPLE SOCIAL MEDIA IMAGES



...organ failure impacts Albertans economically, physically, and mentally





#### SAMPLE SOCIAL MEDIA POST

The sample social media posts and social media images included in this toolkit should be used in tandem.

You can download the images on www.MoreTransplants.ca and share on any social media platform you use.

Below is one example of an image and post you would share online.

@JasonKenney @MinisterShandro @RachelNotey @[YOUR MLA] You have the opportunity to show leadership and save the lives of 1800 Albertans, macro-economic benefit of over \$1 billion dollars (includes cash savings of \$175 million), and end the needless suffering of Albertans on dialysis and waiting for a transplant.





#### Every day...

your family, friends and neighbours are needlessly suffering on dialysis while waiting for a transplant that may never come





## 654 ALBERTANS ARE WAITING FOR A DONOR ORGAN

# THOUSANDS MORE NEED A TRANSPLANT BUT ARE INELIGIBLE



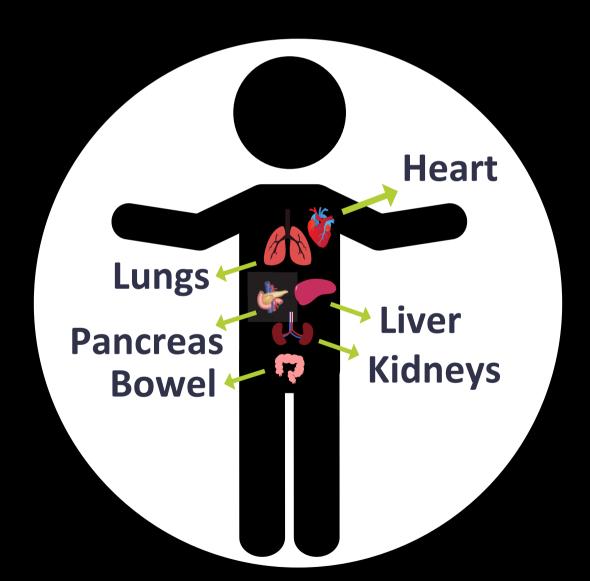






BREATHE the lung association

### ORGANS YOU CAN DONATE



REGISTER. TELL YOUR FAMILY.
MORETRANSPLANTS.CA

### FACING THE FACTS ABOUT

#### **ORGAN DONATION**

WHAT YOU NEED TO KNOW



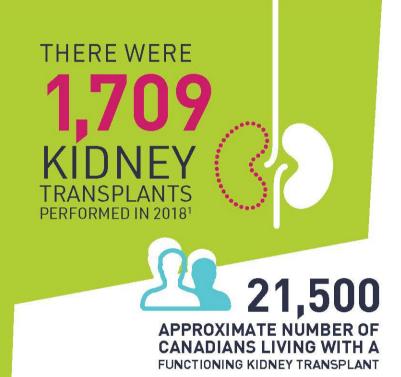
**75**%

OF THOSE ARE WAITING FOR A KIDNEY TRANSPLANT<sup>1</sup>

**28**%

OF KIDNEY TRANSPLANTS ARE FROM LIVING DONORS<sup>1</sup>





#### YOU CAN HELP MAKE A DIFFERENCE

**Register** your intention to donate your organs either through your provincial donor registry, driver's license or healthcare card.

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

Consider living organ donation.

**Join** the Kidney Paired Donation Program Registry at: https://blood.ca/en/organs-tissues.

#### TO LEARN MORE VISIT KIDNEY.CA

\* - Excludes Quebec

Sources: Canadian Institute for Health Information's CORR Annual Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2009 to 2018, www.cihi.ca, supplemented with data collected by the Quebec Branch of The Kidney Foundation of Canada.

1 Canadian Institute for Health Information's CORR e-Statistics Report on Transplant, Waiting List and Donor Statistics 2018, www.cihi.ca.



### THANK YOU.

### YOUR VOICE & YOUR ACTIONS CAN SAVE LIVES.





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