



# GIFTS OF LIFE

## ORGAN DONATION IN ALBERTA

For people who need an organ transplant, the wait can be a long and painful one. But there's something everyone can do to help. Find out more and meet the people in need, the people who give and the medical experts who make transplants happen.

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SATURDAY, NOVEMBER 2, 2019

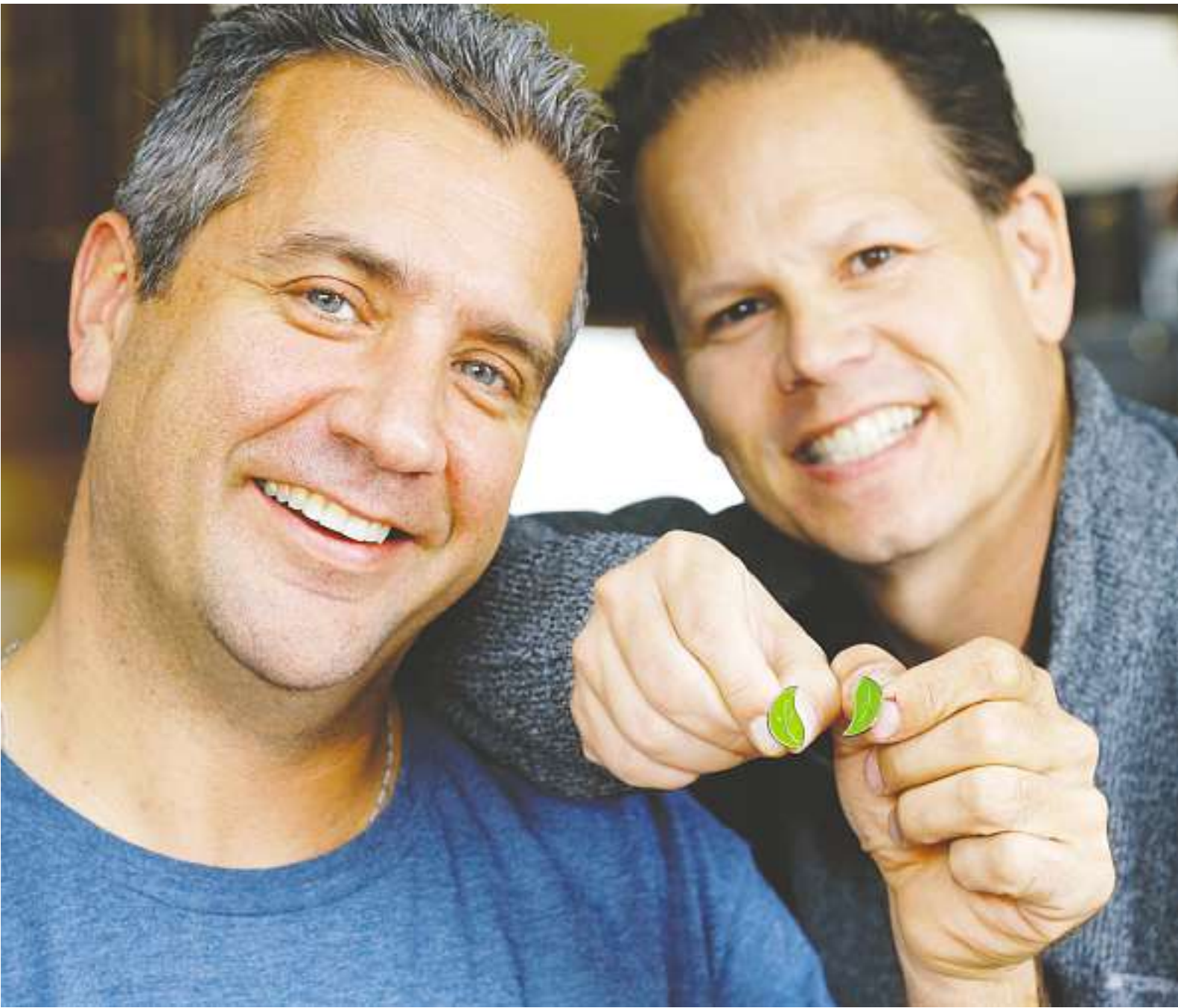
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POSTMEDIA

A SPECIAL REPORT

# GIFTS OF LIFE: ORGAN DONATION IN ALBERTA

Why the gap? The vast majority of people support organ donation, but only one in five actually sign donor cards. **PAGES A13-14-15**



Gifts of Life: Our special series starts today and runs throughout November, shining a light on the need for organ donations. Above, Tony Timmons, left, and Ryan McLennan show the special pins they received after Timmons donated a kidney to McLennan, who had used billboards to advertise his search for an organ. Together, the two partial pins form a whole. And the two men, once strangers, are now the best of friends.

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GIFTS OF LIFE: ORGAN DONATION IN ALBERTA

# Organ, tissue donations remain difficult sell

Surveys show most willing, but fail to sign donor cards

SHAWN LOGAN

It's a confounding statistic that starkly illustrates the challenge facing Canadians in desperate need of life-saving organ transplants. Poll after poll has found nine in 10 Canadians support the idea of donating organs and tissue to those in need, but only around two of those nine have made the conscious effort to sign donor cards.

Poll after poll has found nine in 10 Canadians support the idea of donating organs and tissue to those in need, but only around two of those nine have made the conscious effort to sign donor cards.

Some 675,000 Albertans (about 18 per cent of adults in the province) have registered to become organ or tissue donors, while the province's living donor ratio of 18.5 per million remains among the highest in Canada.

But the gap between cultural acceptance and follow through remains a puzzling one for patients, families and advocates alike, given the potential that exists to meet those demands and provide hope to thousands in desperate need of a life-changing gift.

"It's the power to change people's lives. But the challenge is there's not enough organs to meet the demand," said Joyce Van Deurzen, executive director of the Southern Alberta and Saskatchewan branches of the Kidney Foundation of Canada.

"Every survey done by anyone is saying 90 per cent would be willing to become an organ donor," she said. "I look at this and it all points to the fact that people have good intentions, but we need to compel that into action."

Last year, some 2,800 organ transplants were performed nationwide, 382 of those in Alberta. Meanwhile, nearly 4,500 Canadians were left on the wait list, including 654 from Alberta. Another 643 across Canada (46 in Alberta) died or were removed from those wait lists.

While the challenges posed by limited supply and enduring demand remain something of a bottleneck, great strides have been made to help narrow the gap between prospective donors and transplant recipients in recent years.

According to a background paper on organ donation and trans-



Toby and Bernadine Boulet's son Logan Boulet donated six of his organs after the Humboldt Broncos bus crash on April 6, 2018. Logan had let his father know his wishes of being an organ donor upon death. *DARREN MAKOWICHUK*

plantation prepared for federal legislators last year, deceased donor rates saw a 42 per cent rise between 2007 and 2016, climbing from 485 donors to 758 donors, each of whom could provide as many as eight critical organs: heart, liver, pancreas, intestines and potentially two each of kidneys and lungs.

However, living donor rates have seen a moderate decline over the last decade, dropping by 11 per cent between 2008 and 2017 to 14.6 donors per million population, the report found.

Amber Appleby, director of organ and tissue donation and transplantation with Canadian Blood Services, said while it's encouraging to see the improvements in securing more organs from deceased donors, more can be done to streamline the system and bring home the message on an issue she admits isn't always top of mind for many Canadians.

"We, as a donation community, need to make it easier for people and give them every opportunity to become donors," she said, noting many myths abound when it

comes to becoming an organ donor.

"A lot of people self-exclude because they don't think they would be eligible. We need to make (the process) easier and more consistent."

Among the more common myths and misconceptions related to organ donation is the belief that age and relative health of a prospective donor are always disqualifying factors. And even for those who die in one of the two ways that allow for their organs to be reused — neurological death or cardio-circulatory death — only around one per cent will actually become posthumous donors.

However, the most significant barrier, say advocates, remains the fact most families don't have the conversation with their loved ones regarding their wishes when it comes to organ donations until it's too late. Thus, they will often err on the side of leaving those potentially vital organs and tissue untouched.

For Toby and Bernadine Boulet, whose 21-year-old son Logan was killed in last year's devastating Humboldt Broncos bus crash, they were fortunate enough to have known his wishes before his untimely death.

And that made what could have been a moment of doubt and angst become a moment of peace.

"We really advocate having a conversation and to talk to your family so that people know what your wishes are," said Bernadine.

It was a conversation Logan had with his father Toby, less than a year before his tragic death, that made the decision to donate his organs and tissue less of a burden in the family's darkest hours.

Ultimately, Logan would share six of his organs and tissues, which were able to be successfully transplanted in patients whose lives have now been forever changed thanks to his sacrifice.

Logan's lungs, liver, one kidney, his corneas and his incredibly strong heart — which his parents say refused to stop beating, even after he was removed from life support — all managed to find their way into the donor stream.

It was that sacrifice, during a dark chapter in Canadian history, that spurred what's been called the Logan Boulet Effect.

According to Canadian Blood Services, in the days after the April 6, 2018 crash, some 100,000 people across Canada registered

## ABOUT THE SERIES

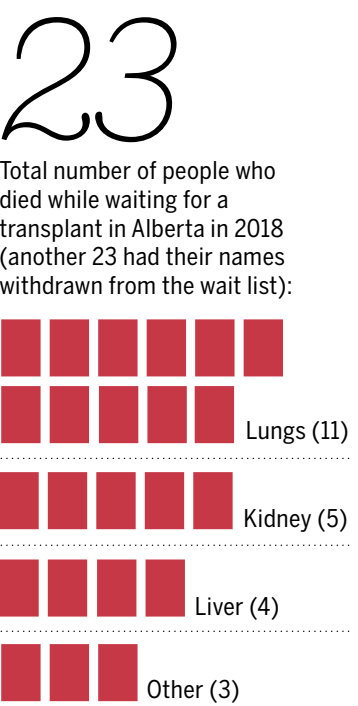
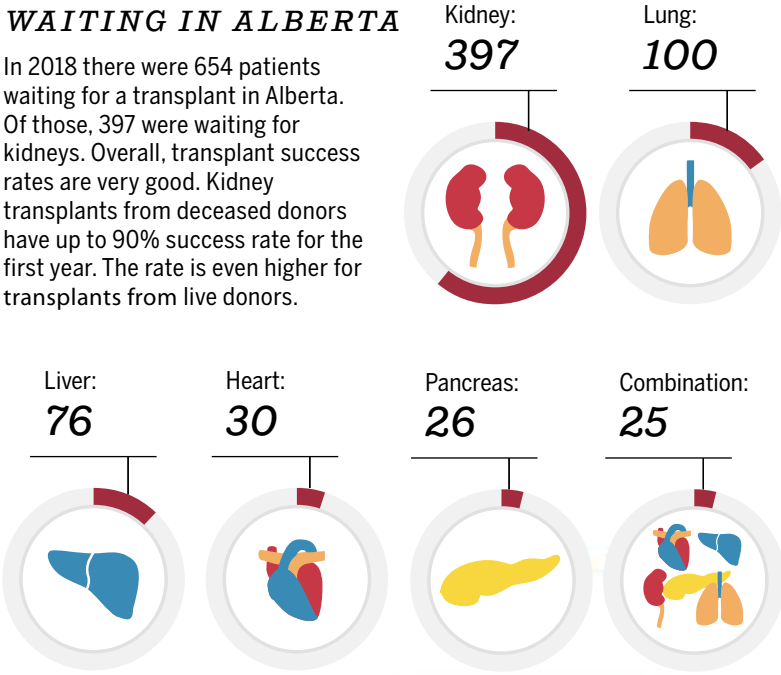
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For more information, stories and videos go to [calgaryherald.com](http://calgaryherald.com).

**Share your story:** We are telling the stories of Albertans and organ donations in print and online throughout November. If you have a story to share — of waiting for, receiving or donating an organ — please email us at [submit@calgaryherald.com](mailto:submit@calgaryherald.com) and include the words "organ donation" in the subject line.

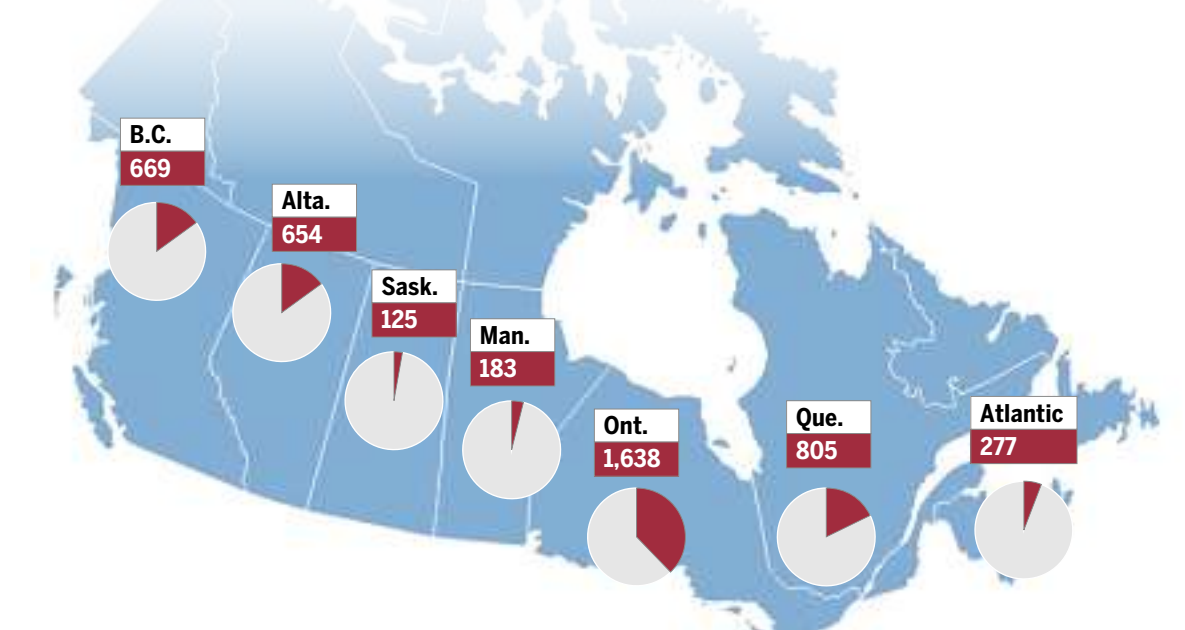
## WAITING IN ALBERTA

In 2018 there were 654 patients waiting for a transplant in Alberta. Of those, 397 were waiting for kidneys. Overall, transplant success rates are very good. Kidney transplants from deceased donors have up to 90% success rate for the first year. The rate is even higher for transplants from live donors.



## WAITING ACROSS CANADA

Nearly 4,500 patients were waiting for a transplant in 2018





GIFTS OF LIFE: ORGAN DONATION IN ALBERTA



Tony Timmons, left, donated a kidney to Ryan McLennan in November 2018 after seeing a billboard asking for an organ donor to come forward for McLennan. PHOTOS: DARREN MAKOWICHUK

# BILLBOARD CAMPAIGN FINDS KIDNEY DONOR

Total stranger sees sign and gives gift of life to 44-year-old shop teacher

SHAWN LOGAN

When 38 airplanes were diverted to Newfoundland and Labrador in the aftermath of the 9/11 terror attacks, Tony Timmons’ parents didn’t hesitate in opening their door to strangers in need.

So when the 48-year-old FedEx driver first saw a billboard last year pleading for a live kidney donor to help Calgary teacher Ryan McLennan, the decision to try and assist a perfect stranger came as naturally for him as it did for his parents and the 12,000 or so other residents of Gander, whose warm generosity was made famous in the Tony Award-winning musical *Come from Away*.

“I was just on the way to work and I see this billboard,” said Timmons, of Airdrie, who on Nov. 28 will mark the one-year anniversary of a successful transplant surgery that gave McLennan a new lease on life.

After seeing the billboard, it prompted Timmons to do some research and soul-searching.

“I just did some Google searching on all the stuff and what it’s all about, and I prayed about it and I said, ‘We’ll see what happens,’” recalled Timmons. “If it were me, what would you do?”

McLennan’s dire plight received significant media attention in February of 2018 when family and friends erected 27 billboards provincewide, along with creating bumper stickers and a social media campaign aimed at unearthing a living donor willing to part with a kidney to give the 44-year-old shop teacher at Father Lacombe high school a shot at returning to a normal life.

He had already had one of his mother’s kidneys successfully transplanted in 2002, but by the end of 2015 McLennan began experiencing health problems and knew he would probably need a second kidney to survive.

“In 2018, just a month after I was married, I went on emergency dialysis and that’s when we started this whole journey to try to find someone that could help me,” McLennan said.

“You really pray for a miracle. You keep thinking, ‘OK something’s going to come up, someone’s going to come forward, like a family member.’ And then when that doesn’t happen, you just keep hoping. And that’s the problem — you’ve got to do more.”

For many people, asking for help



Kidney donor Tony Timmons and recipient Ryan McLennan hold up special pins donors and recipients each get that come together to form a whole.

can be difficult. But the thought of asking someone to have an organ removed from his or her body can be nearly paralyzing.

“I don’t even know how to describe it,” McLennan said. “It took me eight months to ask my brother. It’s almost easier to get someone else to ask, even though it’s your own life, and you’re like you need to take this action.”

“There’s this whole portion that’s constantly going over in your head that something could happen to this person and that’s one of the hardest things,” he said.

Fortunately for McLennan, his wife Shakina wasn’t willing to quietly wait on the sidelines for a

functioning kidney to materialize.

Getting inspiration from another billboard campaign she had seen while travelling to her homeland of Vietnam, Shakina enlisted family and friends to ramp up a public campaign to secure a life-saving kidney transplant for her husband.

“It’s either that, or you die. It’s as simple as that, right?” she said.

“And that’s what I told him. It’s your life, you have to fight for it. To me, it’s more like I would do whatever it takes to get you a kidney.”

And so up went the bright yellow billboards, showing McLennan and his wife along with their beloved Doberman pinscher Athena. “Ryan McLennan needs a living kidney

donor. Blood type O,” was all the message read, along with a phone number and name of the campaign’s Facebook page.

Beyond any of their wildest hopes, the message resonated.

According to the McLennans, the campaign generated more than 150 inquiries resulting in about 30 potential donors put on a list for a battery of testing, including medical, surgical and psychological assessments for those willing to spare a kidney.

Patients requiring kidney transplants historically account for nearly eight in 10 people on national organ wait lists, despite the fact the vast majority of humans can live a

normal life with just one functioning kidney. The organ serves a critical function in helping filter blood and removing waste materials and extra fluid from the body.

As of 2018, one in 10 Canadians was suffering from kidney disease with millions more at risk. Some 48,000 were suffering from kidney failure, with about 3,500 on the organ transplant list. More than 1,600 kidney transplants were performed last year, though another 350 people died or withdrew from the wait list, primarily because they were no longer healthy enough to be a viable candidate for surgery.

Knowing he was on that knife’s edge compelled McLennan to act, with a healthy push from Shakina, despite his own doubts that someone who didn’t even know him would make that kind of sacrifice.

“I had a couple of really close friends and really close relatives and I kept thinking in my mind that if they are not going to test for me, then why would a stranger?” he recalled. “I thought it was the silliest idea in the world. Because, I’m like, I can’t even convince this friend of 25 years to go for a blood test; why would someone do that for me?”

But as the phone calls began coming in, hope began to grow, and he soon found out through a mutual acquaintance that Timmons was undergoing testing to see if he was a match for McLennan.

Then came the day when he learned Timmons was indeed a match.

“I couldn’t believe it. I just sat down in a chair, my class had started, and I was just in awe,” he said.

A few months later, the two men were lying in separate rooms at Calgary’s Foothills hospital, and the life-saving organ was shuttled from Timmons to McLennan.

When the last surgery staple was administered, McLennan’s world changed almost instantly.

“I actually didn’t go to sleep for two days — I just kept walking. I was just on top of the world,” he said. “I was just up and just felt incredible and the nurses ... couldn’t believe it. Everyone was kind of in shock I was doing so well.”

A year later, McLennan is a new man. No longer needing dialysis to clean his blood every other day, he’s returned to teaching and is looking forward to enjoying life to its fullest. And, he now has a new best friend to share that with.

“We see each other two or three times a week. I’m beating him at pickle ball,” said Timmons with a wry smile, when asked about their relationship.

For McLennan, that this lifelong connection grew out of a desperate campaign to save his life continues to leave him awestruck.

“It just blows me away to this day,” he said. “The support that I’ve gotten from Tony and Lisa (Timmons’ wife) is a miracle; it’s really a miracle.”

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On Twitter: @ShawnLogan403



Twenty-seven billboards like the one above went up across the province in February 2018 with the hope someone would be a match and willing kidney donor for Ryan McLennan. AL CHAREST



GIFTS OF LIFE: ORGAN DONATION IN ALBERTA

WHAT YOU CAN DO TO HELP SAVE A LIFE

Saving the life of a fellow Canadian can be as easy as checking a box online or saying yes to being an organ donor when you renew your driver's licence. But, that's just the beginning for those wanting to make a difference.

Deceased donations

In Alberta, individuals over the age of 18 can register their intent to become an organ or tissue donor when they die by using the Alberta Organ and Tissue Donation Registry. (Go to my-health.alberta.ca online and search organ donation registry.) As well, agents and provincial registries are required to ask the donor question when clients are renewing a driver's licence or identification card.

For those who have Alberta Health Cards issued prior to 2018, the back of the card can be signed (with a witness) to declare their intention to donate.

The Alberta registry has been integrated into the province's health-care system through the use of donor co-ordinators. If a person has declared his or her intent to donate and is in a position to be considered for organ or tissue donation, a co-ordinator will discuss it with family members, who ultimately make the final decision.

Each deceased donor can provide up to eight organs (both lungs, both kidneys, liver, heart, pancreas, intestines), while donated tissues can benefit up to 75 individuals.

Living donations

The vast majority of living organ donors spares one of their two functioning kidneys to a person in need, though living liver donations also occur to a lesser extent.

In most cases, family members or acquaintances donate a living organ if they're healthy enough to safely act as a donor. Once a viable donor is found, transplant programs in both Calgary and Edmonton perform the surgeries for kidneys, while live liver transplants are only performed in Edmonton.

There's been a rise in so-called altruistic donors, who are willing to share their organs with a stranger. Both the Kidney Foundation of Canada and Canadian Blood Services can advise prospective living donors on where to turn, while Alberta Health can connect donors to local living donor programs.

Canadian Blood Services also operates the Kidney Paired Donation Program, an interprovincial initiative that maintains prospective donors in a registry if they aren't a compatible match for their intended recipient. Since January 2009, some 500 living donors across Canada have entered the KPD program, including 90 anonymous donors who joined the program without a specific recipient in mind. Non-directed, anonymous donations are responsible for more than two-thirds of the transplants in the KPD program, and all patients with a match have received a transplant in less than a year.

**The Living Donor Services Program – Edmonton:** Phone 780-407-8698; toll free 1-866-253-6833; email: livingdonors@ahs.ca.

**Southern Alberta Transplant Program – Calgary:** Phone 403-944-4635.

**More information on kidney health is available from the Kidney Foundation of Canada:** www.kidney.ca; 780-451-6900 or 403-255-6108.

**More information on liver health is available from the Canadian Liver Foundation:** www.liver.ca; 403-276-3390 or 1-800-563-5483. **Details about Green Shirt Day** and Logan Boulet are at greenshirtday.ca.

Stem-cell donations

Stem-cell transplants replace a patient's unhealthy stem cells with a donor's healthy ones, and can be used to treat cancers and other diseases. The three sources of stem cells are from bone marrow, peripheral (circulating) blood and umbilical cord blood.

Prior to any donation, the donor will undergo a comprehensive health assessment before undergoing the procedure. Peripheral blood stem-cell donation only requires blood to be drawn from a needle in hospital following five days of under-the-skin injections to boost the number of blood cells in the bloodstream.

Bone marrow donations are performed under anesthesia, with hollow needles used to withdraw stem cells from bone marrow in the back of pelvic bones. The procedure lasts between 45 to 90 minutes and the marrow replenishes itself in four to six weeks.

Those who wish to become a stem cell donor can call Canadian Blood Services at 1-888-2-DONATE (1-888-236-6283) or by visiting the agency's website at blood.ca.

Shawn Logan



James Vogel received a kidney from an anonymous donor after a three-year search, which was aided by advertising, like the sticker on the back window of his family's Dodge minivan. He underwent the transplant Oct. 16 at Foothills Medical Centre. PHOTOS: AZIN GHAFARI

Desperate Albertans get creative in looking for living organ donors

Vehicle stickers, social media campaigns and roadside billboards advertise need

SHAWN LOGAN

The bold white and green billboard was hard to miss for visitors descending into the Drumheller valley over the last few months.

"Someone we love needs a kidney donor. Type A+."

What started as a sticker on the back of the Vogel family's burgundy Dodge minivan last year spurred the badlands oasis into action, starting with a prominent rinkside ad erected by the Drumheller Dragons junior A hockey team. It grew into a video playing before films at the local Napier movie theatre and eventually made its way on to a fleet of transport trucks operated by Calgary-based Hi-Way 9, taking the plea provincewide.

But it was the billboards — the final piece of the puzzle in a desperate campaign to find a living kidney donor for 35-year-old James Vogel — that finally helped secure the precious, life-saving gift.

"There's no words to describe how it all came together, how the universe just pulled it all together," said Vogel, a week after he underwent successful transplant surgery at Calgary's Foothills Medical Centre on Oct. 16.

"It just happened so fast." The donor, an anonymous Calgary woman, was motivated to undergo testing after seeing the billboard that greets tourists to the town known for being home to the famed Royal Tyrrell Museum and the world's largest dinosaur replica. With thousands of Canadians waiting for organ transplants every year, some are no longer willing to patiently wait for their turn in the queue.

Social media, marketing and creative planning are becoming more common as the number of patients in need regularly outstrips the number of organs available. It's become especially true for those like Vogel, suffering kidney failure, because a matching live donor can quickly restore a critical function that otherwise has to be simulated by regular and often painful dialysis treatments, which in some cases can continue for several years.

In Calgary, high school shop teacher Ryan McLennan was able to secure a kidney from a stranger who saw one of the 27 billboards his loved ones had erected around the province, as they opted to take an aggressive approach to the problem.

In 2018, some 1,600 successful kidney transplants were performed across Canada, slightly less than 200 of those in Alberta. Meanwhile, more than 3,000 people languished on a wait list, including some 400 in Alberta.

Amber Appleby, Canadian Blood Services' director of organ and tissue donation and transplantation,

said she's well aware that patients on organ transplant waiting lists are becoming much more proactive about seeking donors instead of quietly biding their time on the wait list.

And that comes with its own challenges.

"People are reaching out on social media and different venues to do that," Appleby said.

"It has its advantages and disadvantages. Local transplant programs encourage people to do it, but to be careful. There are a number of ethical issues we need to be careful about."

It's not unusual, Appleby said, for people to try to take advantage of others who make their situations public by trying to leverage that need for some quick cash. As well, in some cases that have a high profile — like Ottawa Senators' owner Eugene Melnyk's quest for a living liver donor in 2015 — the intake system can be overwhelmed.

For the Vogels, who have two young children, the decision was an easy one: fight or die.

"We have had some people I can't say have been supportive in all the ways because, of course, there are people that are battling it that have been longer than us, but that's why we put it in our hands because we knew the waiting is very long," said Tanya, who pressed husband James to bring his story to the public in hopes of securing a kidney. "So we put it in our own hands — he's young enough, he has two young kids. I did whatever I had to do," she said.

Edmonton's Chris Charles knows all about waiting.

The 44-year-old graphic designer has been in dire need of a new kidney since he experienced a series of medical complications three years ago, culminating in a diagnosis of



Chris Charles

“They told me, ‘Don’t expect a kidney in a year; expect more like five or seven years.’ It was like a reality check.”

kidney failure on Feb. 21, 2017.

Since then, he's toiled on an organ transplant wait list while his ability to perform even the most mundane daily tasks deteriorates.

He spends four to five hours, three days a week, in a dialysis suite where he receives life-preserving dialysis treatments, while toxins are cleaned from his blood.

The waiting never gets easy, Charles said. And that's what prompted him to take control of his situation.

"They told me, 'Don't expect a kidney in a year; expect more like five or seven years.' It was like a reality check," he said. "I kept thinking something is going to happen. I kept thinking maybe my situation was going to be different."

Pride, Charles said, was one of his biggest hurdles. Almost as much as the soul-crushing fatigue, draconian dietary restrictions and regular dialysis treatments he likens to "jail."



Tanya Vogel pressed her 35-year-old husband James to go public with his need for a living kidney donor. "We put it in our own hands — he's young enough, he has two young kids. I did whatever I had to do," she says.

Once he overcame that, however, he found nothing but support.

"I've never asked anyone for help for anything in my life," he said. "But it scared me to death thinking this is what my life is going to be now. I realized it was a fact that nobody was going to help me if I don't ask."

He took to social media, giving friends, acquaintances and the public a sometimes painfully candid glimpse into his daily life as someone experiencing renal failure.

Despite the daily rigours of his disease, he continues to provide updates while he continues his own pursuit of a life-changing kidney donation.

For the Vogels, now adjusting to a new and happy reality in which James has a new lease on life, the lesson learned from their quest for an organ donor is one they suggest others can emulate.

Even as James recovers from surgery, and they look to return to a normal life, he said they plan to keep the signs and stickers up, hoping at the very least to educate more people about how choosing to donate an organ can transform a life.

"Don't suffer in silence. Get out there and ask, you know, spread your story, share your story or just outright talk about it," he said.

"We're going to push it even more now than ever because I want people to know you don't have to suffer in silence. You can save a life — it's proven right here."

If you're interested in testing to be a potential kidney donor for Charles, call 1-780-407-8698, ext. 3, and tell them you would like to be tested. Those who aren't a match but would still like to donate can enter the kidney paired donation program, which allows a potential donor to donate to another person in need. For more information on the paired program, call 1-780-777-4119.

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GIFTS  
OF LIFE

PART 2 OF 5

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For more information, stories and videos go to **calgaryherald.com**.

SHARE  
YOUR STORY

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ORGAN DONATION IN ALBERTA



Dr. Dennis Djogovic, medical lead for the Human Organ Procurement and Exchange (HOPE) program, says he's amazed at the families “that can take a situation that they're in and try and find a way that the death of their loved one may lead to a legacy that continues beyond their life.” *IAN KUCERAK*

# TRANSPLANTING EXCELLENCE

Donors, families and a nexus of experts comprise the heart of U of A Hospital's expertise

MOIRA WYTON

It was a busy evening honouring the families of organ donors in Alberta when Dr. Dennis Djogovic ran into a family he had not seen since their young relative passed away earlier that year.

The family had struck Djogovic the moment he met them in the intensive care unit at the University of Alberta Hospital. Their loved one had been young, yes, but their desire to ensure he became an organ donor — as he had wanted — was what made the greatest impression on Djogovic.

Months later, the family greeted Djogovic warmly, remarking on how special it was to celebrate their loved one's legacy amid their grief.

“The fact that we could keep talking about him and recognize that his donation had gone on to help others was a huge moment of pride for the family in that very difficult circumstance,” said Djogovic, an intensivist at the University of Alberta Hospital and medical lead for the Human Organ Procurement and Exchange (HOPE) program.

Stories such as the one told by Djogovic — and the people involved in each of them — are what compose the beating heart of Alberta's organ donation and transplantation system at the University of Alberta Hospital, the largest and most comprehensive organ and tissue transplant program in Canada.

Home of the Alberta Transplant Institute, the hospital is ranked sixth in the world for transplanting excellence in clinical care and research. In terms of patient outcomes, it ranks in the top 10 per cent worldwide.

Last year, doctors at the U of A performed 353 organ transplants — including heart, lung, islet, kidney, liver, pancreas, eye, tissue and small intestine transplants — on patients of all ages and genders from across Alberta and Western Canada. Every kind of organ and tissue transplant, except for cornea transplants, are performed at the hospital.

Among the 421 transplants from 155 individual donors performed in Alberta in 2017, there were 67 lung transplants, 130 kidneys transplanted from deceased donors and two combined heart and lung transplants.

Each operation requires hundreds of specialists — physicians, transplant co-ordinators, nurses



Doctors Jayan Nagendran, left, and Darren Freed developed a clinical trial of a portable ex-vivo system, shown, that allows doctors to repair lungs for transplant at the site they are recovered, potentially increasing the number of donor lungs that can be used to save lives. *ED KAISER*

and more — to work to save a life in time frames as tight as a few hours.

“Time is both on your side and against you, at the same time,” said Djogovic from his office in the hospital.

It took many years for the U of A to become the empathetic epicentre of excellence that it is today — and it matters most to the hundreds of patients and donors who are in its care each year.

But what makes the U of A hospital unique in Canada and around the globe are the world-

class doctors who are practising and researching at the same time, allowing them to be at the edge of innovation in a variety of areas related to transplantation, said Dr. Darren Freed, a cardiac surgeon clinician-scientist.

“One of the secrets is the fact that this institution has a very high concentration of researchers, basic scientists and clinicians working together on transplantation in a single institution,” said Freed.

These experts range in scale of study from the cellular component

“Transplantation is an incredibly rewarding activity and every day we transform patients' lives,” says Dr. James Shapiro, a liver transplant surgeon at the University of Alberta Hospital and director of the Living Donor Liver Transplant program. *CLAIRE THEOBALD*

of transplantation to the functioning of a multi-organ system, he said.

“Whether that is looking at prolongation of organ donation function through external perfusion techniques at the research level and also in a clinical setting, to therapies to make immunosuppressive drug regimens more tolerable and more successful for patients that have received transplants ... all of that happens here locally,” said Djogovic.

“It makes us a worldwide centre.”

Some current transplantation practices common around the world were born in Edmonton, while others are also on the cusp of becoming utilized globally.

A clinical trial of a portable ex-vivo system to allow doctors to assess and repair imperfect donor lungs at the recovery site by Freed and Dr. Jayan Nagendran at the U of A, for instance, has the potential to vastly increase the quantity and quality of donor lungs that can be used for transplant.

Currently, less than 25 per cent of donor lungs are viable for transplant, and one in three of the approximately 100 patients on the list for a lung transplant in Alberta dies before a donor becomes

available.

Most recent statistics from the Canadian Institute for Health Information in 2017 show that Canada has “a shortage of organs,” with 4,333 patients on the wait-list for a transplant and 242 Canadians dying while waiting for a transplant that year.

In 2014, the province launched an online organ donation registry in Alberta, to combat what were declining rates of organ donation.

“We want to have the leading rate in the country. The goal is to have all the supply that we need for organ and tissue donation for Albertans, and then some,” said then-minister of health Fred Horne.

Between 2008 and 2017, the number of individual donors in Alberta increased by nearly 50 per cent from 104 to 155. In 2016, Alberta set a record for most deceased organ donors in one year at 70 — 16.1 per million people — but still lagged the national average of 20.9 donors per million.

“I think we need to start with where the need is,” said Djogovic, whose role at HOPE includes both advocacy and support work for patients and donor families, alongside medical direction. “And the need is that there are Albertans and there are Canadians out there who are dying because of organ failure.”

Policy changes have contributed to making once unthinkable transplants possible, said Sean Delaney, the associate director of organ listing and allocation at Canadian Blood Services.

The creation of a streamlined Canadian Transplant Registry has opened space for information sharing between provinces and for innovative new approaches to finding matches.

The Kidney Paired Donation Program matches willing but mismatched donor-recipient pairs with other pairs across the country to find a combination of pairs that will allow all recipients to receive a kidney that matches essential antibody characteristics.

The program, which has facilitated more than 700 transplants since launching in 2012, was barely in the realm of possibility 15 years ago, Delaney said.

And new ground continues to be broken at the U of A Hospital each day, such as the Living Donor Liver Transplant Program headed by the internationally recognized Dr. James Shapiro.

SEE EXCELLENCE ON **A14**



ORGAN DONATION IN ALBERTA

EXCELLENCE FROM A13

The program works to reduce the number of patients who die waiting for a liver transplant by expanding the donor pool to living donors.

Healthy donors can regenerate the donated portion of their liver within about one week, Shapiro said, and about 25 per cent of patients die waiting for a liver transplant. “Transplantation is an incredibly rewarding activity and every day we transform patients’ lives that were previously on death’s doorstep, and patients who receive these transplants are so incredibly grateful,” he said.

Delaney knows the challenging realities of organ transplants all too well. Born with a bladder blockage that caused one of his kidneys to fail as an infant, he received a donated kidney from his brother in 1998 in a pre-emptive transplant when he was 28.

Complications followed, but his quality of life was vastly improved after the initial transplant and remained stable until last year.

“There’s far more technology around today and programs to support an individual so that living a long life on a transplant is truly a possibility,” said Delaney, now 48.

Since this past August, Delaney has been on dialysis and has been re-added to the list for a second kidney transplant. So far, he notes that 25 potential donors — whom he did not previously know — have reached out through his posts on social media, where he is documenting his journey.

“That’s 25 people who are otherwise healthy, who don’t need to have surgery, who are willing to go under a knife for nothing but saving my life,” said Delaney. “That’s pretty humbling.”

The Logan Boulet effect — named after the Humboldt Broncos player whose donated organs were used to save six people after the fatal bus crash in 2018 — is one event Delaney credits with kick-starting vital conversation around organ donation in Alberta.

“People don’t want to talk about death and dying,” said Delaney, noting that tens of thousands of Canadians signed up to be donors after hearing about Boulet’s wishes to be an organ donor.

It’s an essential conversation, Djogovic added, because the advances made in medicine at the U of A would be nothing without the altruism of living and deceased organ donors and their families. They continue to seed new beginnings for patients from tragic circumstances.

“I’m always amazed and impressed at the families that can take a situation that they’re in and try and find a way that the death of their loved one may lead to a legacy that continues beyond their life,” said Djogovic.

Ultimately, what drives transplant doctors at the U of A to complete countless iterations of a device and hours of research and patient care is the opportunity to make the most of these gifts of life — for patients now and in the future.

“Clinicians and scientists work to honour those donors in the greatest way possible,” said Nagendran. “And the greatest way to honour those donors is to use as many of those precious gifts that they are offering.”

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DAVID BLOOM

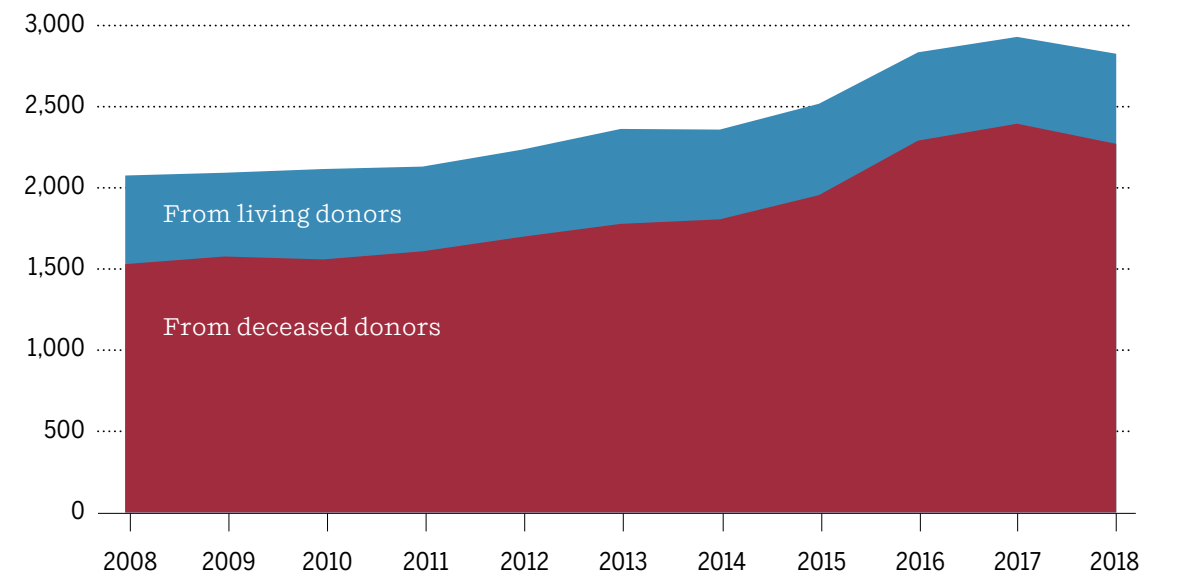


“Tomorrow’s not guaranteed for anyone. I’d rather go knowing I had done everything I can.”

KENDRA LEE-RANKIN, above, who has been waiting for a heart transplant for over a year. At left, Lee-Rankin, after her first heart surgery at five days old.

ORGAN TRANSPLANTS IN CANADA

Organ transplants have been steadily rising over the past decade, but took a significant dip in 2018.



SOURCE: CANADIAN INSTITUTE FOR HEALTH INFORMATION

DARREN FRANCEY / POSTMEDIA

HEATHER ZIRK wants more families to talk about organ, tissue donation

MOIRA WYTON

A hospital is an unconventional place for a wedding, but it was exactly where Dr. Harry Zirk’s youngest daughter and her fiancé wanted to get married.

It was the summer of 2018 and Zirk had been in the Royal Alexandra Hospital in Edmonton for a week after suffering a heart attack while he was on dialysis for ongoing kidney failure.

The couple were in the hospital among family and friends on the Thursday after Zirk was admitted.

“Everyone went home from the hospital smiling instead of bawling for once,” his wife, Heather Zirk, said of the wedding. It had been a challenging time for the family, as Zirk’s life was close to the end.

The two began dating in Calgary



Heather Zirk

while they were in high school. They celebrated 40 years of marriage before Zirk passed away July 22, 2018, after a month in hospital.

But being a medical family — Heather was a registered nurse before she retired — the two had long discussed her husband’s wish to donate his organs and tissues to someone who could use them.

Now, Heather is advocating for families to have these types of conversations before they become a necessity, for their own sakes and those of the transplant patients whose lives could be saved.

When Zirk’s illnesses, including diabetes and kidney failure, made it clear his organs would not be in good enough condition to be donated, they chose to gift his body to the University of Alberta medical school through the anatomical gift program.

“It’s a tougher decision when their heart is beating and they’re warm,” Heather said, stressing the importance of discussing organ and tissue donation as early as possible.

When Zirk passed away, the anatomical gift program was unable to accept his body at that time, so



instead Heather was put in touch with the tissue donation program. Zirk’s corneas, long bones and connective tissues were retrieved.

Heather later learned his corneas gave someone the gift of sight, and his long bones helped 14 people undergoing joint replacements.

It eases Heather’s grief to know her husband is still helping people after his death — similar to how he’d always helped people in life as a doctor. The process has also given her a new appreciation for

Dr. Harry Zirk helped people after his death as he helped people in his life as a physician, says his wife, Heather. LARRY WONG

how important it is to have these conversations with loved ones before they are gone.

“Harry could appreciate what we’re supposed to get out of life and certainly helping other people is kind of one of the things that was important to him,” said Heather. “I think things happened exactly the way he would have wanted it to happen.”

KENDRA LEE-RANKIN Advocacy, health and living life

MOIRA WYTON

Kendra Lee-Rankin and her now-husband Scott were eating Dairy Queen food at their kitchen table in St. Albert when she pulled out an onion ring and proposed in early 2019.

Scott thought she was joking, but Lee-Rankin, 28, was dead serious. “I want to live as much life as I can,” she said of the reason behind her spontaneous proposal.

Since being added to the list for a heart transplant in June 2018, Lee-Rankin’s default setting has become one of taking life by the horns, and that includes advocating for as many people as possible to register to be organ donors.

Born at BC Children’s Hospital in Vancouver, she had her first open heart surgery when she was just five days old to fix a birth defect that caused the two great arteries in her heart to not cross, preventing her blood from being properly oxygenated.

By 22, when she had a pacemaker inserted, she’d had more than 14 surgeries.

“I didn’t really know any different,” she said of her childhood, during which she loved playing with friends, but often couldn’t keep up. “It would be nice to know what normal is.”

Lee-Rankin and her husband wed in September, and the two hope to have children. They plan to adopt, since her heart failure would put both hers and a baby’s life at risk if she became pregnant.

In the meantime, she is focused on her health. She’s had to stop working at Lowe’s, due to the physical toll, and her days have been centred on caring for herself and managing her pain. Still, she loves the idea of having a purpose in caring for a child, and finds it by doing regular respite work with a friend’s young son, who has physical disabilities.

Her journey has been full of challenges, including the fact her small stature makes her a very particular match for a heart. However, the quest for a transplant has brought her family together in its advocacy to promote organ donation and highlight the need to support medical causes.

“There isn’t enough information out there about organ donation,” she said, stressing that many may not believe it could be themselves or a family member in need of a transplant. “It’s a non-subject.”

It’s a topic Lee-Rankin talks about whenever she can, along with doing everything possible to enjoy life. Right now, that includes making plans for a honeymoon — before or after a potential transplant — and the possibility of growing old with her husband.

“Tomorrow’s not guaranteed for anyone. I’d rather go knowing I had done everything I can.”

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ORGAN DONATION IN ALBERTA



A group of Europeans at Odminių Square in Vilnius, Lithuania, light candles to mark an event in support of organ donation and transplants. Raising awareness of the need for hearts and other organ donation is crucial, says Tanya Sumka, a mother of two who is waiting for a donor heart. *PETRAS MALUKAS/AFP VIA GETTY IMAGES*

# TANYA SUMKA

## A heart transplant is more complex than waiting on a list

MOIRA WYTON

Since Tanya Sumka’s children were young, she has reminded them — whether they’re making homemade perogies or doing laundry — “you need to know how to do this, in case I’m not here.”

In earlier years, they assumed it was because she might be in the hospital. When her daughter was an infant 12 years ago, Sumka was diagnosed with viral cardiomyopathy — an infection that causes acute inflammation and weakness of the heart muscle.

Over the years, Sumka’s condition worsened, but she continued to try to live as normal a life as possible. She took her two children to Ukrainian dance lessons and enjoyed spending time with her husband on their acreage.

However, three years ago — around the time she had a left-ventricular assist device (LVAD) in-

serted — Sumka was shocked to learn from doctors that she would need a heart transplant in the long term.

“It was like a punch in the gut,” Sumka said of the moment she received the news. “What’s life like after a transplant? It’s a world of the unknown.”

Since August 2018, Sumka has been awaiting a heart transplant in the hope she can be there for her children as long as possible. For now, she is connected to the LVAD 24 hours a day, limiting her mobility.

Her story highlights the challenges faced each year by about 500 Albertans on a transplant list who are waiting for a call that could change their lives.

What does the prospect of a heart transplant mean to Sumka? “To have a second chance at still having the life that I know, that I potentially could have another 20

years to see my children grow up (and) to give meaning to whatever part of life I still have,” she said. “That’s my dream.”

Sumka acknowledges a transplant is no easy fix. For those in need of a heart, it requires months or even years of recovery from a taxing and complex surgery. And it means taking a laundry list of medications for the remainder of one’s life.

Some days, she said, the enormity of the procedure overwhelms her, as does the reality that a donor life will be lost if she receives a heart.

“There’s tragedy that comes with the gift of life,” Sumka said. “And it’s a very hard thing to get around.”

The support of the medical and transplant teams at the University of Alberta Hospital and Mazankowski Heart Institute has been invaluable on those days of doubt and struggle, she said. “They are



Tanya Sumka says she pulls through the difficult days of waiting for a heart transplant by thinking of her children, Victor and Ivonna. *TANYA SUMKA.*

passionate with all their patience,” Sumka said of her medical team.

She hopes that by sharing her story, she can spread awareness of the challenges of being a transplant patient when “it is so much more complicated than being on a list.”

Most people Sumka talks to don’t understand it’s not as simple as waiting her turn. “It is a miracle. And you have the responsibility to make the most of it, because it’s (the donor’s) legacy.”

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# SEAN DELANEY

## An advocate and a transplant recipient

MOIRA WYTON

When Sean Delaney arrived at the University of Alberta hospital during the summer of 1999, he didn’t expect his visit to the emergency room to lead to a decades-long partnership in research and advocacy.

It was less than a year after he’d received a pre-emptive kidney transplant from his brother at age 28 and he was suffering from a condition no one could yet diagnose.

But Dr. Sandra Cockfield, who was on rounds that evening, called in colleagues from multiple departments and was able to come up with a correct diagnosis — a rare form of non-Hodgkin’s lymphoma — and care for his kidneys.

“She’s quietly been one of my own personal heroes, just for being exactly the right person at the right time,” said Delaney, now 48.

Since that night, Cockfield has gone on to publish work on Delaney as his transplant doctor, in



Sean Delaney, an associate director in the Canadian Blood Services organ and tissue division, is awaiting a second kidney transplant. *LARRY WONG*

the hopes it could help patients with similar medical challenges.

Delaney, in turn, is also working to assist others who face transplants across the country. Now the associate director of organ

listing and allocation at Canadian Blood Services, Delaney works to streamline organ donation across the country and create new ways to help people receive the organs they need to live and thrive.

This has included the creation of a national registry to administer new programs such as the Kidney Paired Donation Program, which has facilitated more than 700 transplants since its founding in 2009.

“What it meant is a whole new way to obtain an organ transplant, if you had a living donor that was unable to donate to you,” he said.

Another program, begun in 2015, facilitates kidney sharing Canada-wide for 567 patients who have high antibody counts — a condition that increases the difficulty of a match being found for these individuals, such as Delaney himself.

“It was a very high-need group that was not going to get transplanted on local lists alone,” said Delaney, noting the program allocates existing transplants. “They needed access to a full national donor pool to make it work.”

Delaney’s medical journey is far from over. His kidney has been in failure within the last year and he

went back on peritoneal dialysis over the August long weekend.

Now, Delaney is back on the transplant list — including the hepatitis C-positive list — and utilizing social media to locate potential donors. He has found about 25 so far, but it has made him keenly aware of how important it is for organ donation to become the norm rather than the exception in Canada.

“Ultimately, you need patient advocacy and donor campaigns to save lives,” said Delaney.

Beginning the transplant process again has been challenging, he said. Most of his colleagues are used to seeing him as an advocate, not a patient. But he finds reward and strength in combining those roles in his work.

“You can’t get into too many topics where there isn’t some sort of a relationship back to your own personal experience,” he said. “You are definitely impacting patients that look a whole lot like you.”

# What you can do to help save a life

Saving the life of a fellow Canadian can be as easy as checking a box online or saying yes to being an organ donor when you renew your driver’s licence. But that’s just the beginning.

### DECEASED DONATIONS

In Alberta, individuals over the age of 18 can register their intent to become an organ or tissue donor when they die by using the Alberta Organ and Tissue Donation Registry. (Go to [my-health.alberta.ca](http://my-health.alberta.ca) online and search organ donation registry.) As well, agents and provincial registries are required to ask the donor question when clients are renewing a driver’s licence or identification card.

For those who have Alberta Health Cards issued prior to 2018, the back of the card can be signed (with a witness) to declare their intention to donate.

The Alberta registry has been integrated into the province’s health-care system through the use of donor

co-ordinators. If a person has declared his or her intent to donate and is in a position to be considered for organ or tissue donation, a co-ordinator will discuss it with family members, who ultimately make the final decision.

Each deceased donor can provide up to eight organs (both lungs, both kidneys, liver, heart, pancreas, intestines), while donated tissues can benefit up to 75 individuals.

### LIVING DONATIONS

The vast majority of living organ donors spares one of their two functioning kidneys to a person in need, though living liver donations also occur to a lesser extent.

In most cases, family members or

acquaintances donate a living organ if they’re healthy enough to safely act as a donor. Once a viable donor is found, transplant programs in both Calgary and Edmonton perform the surgeries for kidneys, while live liver transplants are only performed in Edmonton.

There’s been a rise in so-called altruistic donors, who are willing to share their organs with a stranger. Both the Kidney Foundation of Canada and Canadian Blood Services can advise prospective living donors on where to turn, while Alberta Health can connect donors to local living donor programs.

Canadian Blood Services also operates the Kidney Paired Donation Program, an interprovincial initiative that maintains prospective donors in

a registry if they aren’t a compatible match for their intended recipient.

Since January 2009, some 500 living donors across Canada have entered the KPD program, including 90 anonymous donors who joined the program without a specific recipient in mind. Non-directed, anonymous donations are responsible for more than two-thirds of the transplants in the KPD program, and all patients with a match have received a transplant in less than a year.

**The Living Donor Services Program – Edmonton:** 780-407-8698; toll-free 1-866-253-6833; email: [livingdonors@ahs.ca](mailto:livingdonors@ahs.ca).

**Southern Alberta Transplant Program – Calgary:** 403-944-4635.

**More information on kidney health is available from the Kidney Foundation of Canada:** [www.kidney.ca](http://www.kidney.ca); 780-451-6900 or 403-255-6108.

**More information on liver health is available from the Canadian Liver Foundation:** [www.liver.ca](http://www.liver.ca); 403-276-3390 or 1-800-563-5483.

**Details about Green Shirt Day** and Logan Boulet are at [greenshirtday.ca](http://greenshirtday.ca).

**STEM-CELL DONATIONS**

Stem-cell transplants replace a patient’s unhealthy stem cells with a donor’s healthy ones, and can be used to treat cancers and other diseases. The three sources of stem cells are from bone marrow, peripheral (circulating) blood and umbilical cord blood.

Prior to any donation, the donor will undergo a comprehensive health assessment before undergoing the procedure. Peripheral blood stem-cell donation only requires blood to be drawn from a needle in hospital following five days of under-the-skin injections to boost the number of blood cells in the bloodstream.

Bone marrow donations are performed under anesthesia, with hollow needles used to withdraw stem cells from bone marrow in the back of pelvic bones. The procedure lasts between 45 to 90 minutes and the marrow replenishes itself in four to six weeks.

Those who wish to become a stem cell donor can call Canadian Blood Services at 1-888-2-DONATE (1-888-236-6283) or by visiting the agency’s website at [blood.ca](http://blood.ca).

*Shawn Logan*



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LIFE



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Canola fields inspired a complex novel **G10**

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IS BACK

Cable cult fave returns with series on YouTube **D1**



TRUMP ADVISER FOUND GUILTY

Jury convicts Stone on all charges **NP1**



SATURDAY, NOVEMBER 16, 2019

ESTABLISHED 1883

POSTMEDIA

‘YOU HAVE TO BE THERE’

In an interview with columnist Don Braid, Alberta premier’s principal adviser defends his business trips to London to attract investment **A3**



IAN KUCERAK

CHERISHING THE GIFT

Lung transplant recipient Doug Pearson used his Trek bike to complete the 122-km Gran Fondo bike ride last summer. For more about his story and to learn about what you can do to help save a life, see pages **A12-14**.



MUSIC

Calgary-born Alice talks defiance, new album **D2**

TRAVEL  
More than just beaches in Grenada **E1**



LACROSSE  
Roughnecks set for NLL title defence **B2**

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FLAMES

Teammates reflect after Brodie’s collapse **B1**



GIFTS OF LIFE

PART 3 OF 5

- Nov. 2: Social media and marketing: A new era of organ donations
- Nov. 9: Alberta's centre of transplant excellence
- Nov. 16: After transplantation: New leases on life
- Nov. 23: How organ donation works in Alberta
- Nov. 30: Opt in, opt out: How to better meet a critical need

For more information, stories and videos go to [calgaryherald.com](http://calgaryherald.com).

SHARE YOUR STORY

We are telling the stories of Albertans and organ donations in print and online throughout November. If you have a story to share — of waiting for, receiving or donating an organ — please email us at [submit@calgaryherald.com](mailto:submit@calgaryherald.com) and include the words “organ donation” in the subject line.



Miranda McLeod's son, Tanner, has been diagnosed with a rare blood disease. The Manitoba family is now awaiting a suitable volunteer donor for a stem cell transplant for the five-year-old boy. KEVIN KING

# LIVES on the LINE

Health advocates work to improve ethnic diversity in stem cell registry and its donor pool

MYTH BUSTING

Donor advocates say a variety of reasons exist as to why Canadians are hesitant to join the stem cell registry. One of the most prevalent is misinformation about the procedure. Here are some myths they're hoping to dispel.

**Myth Stem cells are taken from the spinal cord** There are three sources for stem cell donation: Peripheral (circulating) blood, bone marrow or umbilical cord blood. In the case of a bone marrow donation, stem cells are collected from the iliac crest, which sits at the back of the pelvic bone. The spinal cord is unaffected.

**Myth All stem cell donations involve surgery** Bone marrow donation is the only surgical procedure.

Peripheral blood donation, which makes up the majority of cases, is a non-surgical procedure where a donor's blood is removed through a sterile needle in one arm. Cord blood donation is the least invasive method and is collected from the umbilical cord following the birth of a healthy baby.

**Myth Stem cell donation is painful and involves a lengthy recovery process** Donors do not experience pain during any of the stem cell donation procedures, according to Canadian Blood Services. Recovery varies depending on the type of donation, but generally donors are back to their usual routine within a few days or, at most, a few weeks.

Bone marrow donors are expected to feel some soreness in their lower back and some people have reported feeling tired or having discomfort walking. Peripheral blood donors have reported symptoms including headaches, bone or muscle pain, nausea, insomnia and fatigue, but the effects usually disappear shortly after donating.

**Myth Stem cells are not replaced once they are donated** The human body replaces stem cells within six weeks.

**Myth People needing a stem cell transplant can easily find a match within their family** Only 25 per cent of people are likely to find a match within their family.

Alanna Smith

ALANNA SMITH

It's no wonder five-year-old Tanner McLeod is infatuated with superheroes, considering he's looking for a hero of his own.

Tanner was diagnosed with a rare blood disease called sideroblastic anemia at six months old and his family has been searching for a stem cell donor ever since.

He can't play like other kids his age as he struggles with fatigue, decreased appetite and a weak immune system. Many of his days are spent attached to a machine pumping fresh blood into his little body. In order to beat the disease, he has to find his “genetic twin” and receive a stem cell transplant. However, the chances of doing so are nearly impossible.

His mom, dad and brother weren't a match — despite a 25 per cent likelihood of matching with a sibling — and no suitable donor has been found in the Canadian stem cell registry of about 450,000 people, or the global registry of roughly 29 million.

The young boy is from the Pimicikamak Cree Nation, also known as Cross Lake in Manitoba, and he is significantly more likely to find a match within his own Indigenous community.

The Canadian registry through Canadian Blood Services (CBS) lacks a diverse donor pool, with two-thirds of registrants being Caucasian. First Nations, Metis and Inuit potential donors account for only 1.3 per cent of registrants.

It's the reason his mom, Miranda McLeod, and others across the country are organizing community donor drives to encourage ethnically-diverse individuals to join the national registry. It's why McLeod remains optimistic.

“I'm pretty confident his match will be found sooner or later,” she said.

Stem cells — which are immature cells that transform into red or white blood cells and platelets — are used to treat diseases and conditions of the blood and immune system such as leukemia, lymphoma and aplastic anemia. In order to find a match, a patient and donor must have almost identical DNA markers called Human Leukocyte Antigens.

Some are luckier than others. Susan Nguyen, for example, was a match for her younger brother Bille Nguyen who was diagnosed with T-cell lymphoma in 2018. He was given a 10 per cent chance of survival without a stem cell transplant and finding a Vietnamese-Chinese match had discouraging odds as well.

The aggressive cancer forced Bille to undergo multiple rounds of chemotherapy but, despite treatment, the cancer continued to spread. His immune system was



JOIN CANADA'S LIFELINE

Joining the national stem cell network is easy.

All applicants need to do is register to donate at [www.blood.ca](http://www.blood.ca) and complete a health screening questionnaire. Once this is complete, registrants will be sent a swabbing kit to collect a DNA sample, which is then returned to Canadian Blood Services. Applicants will be notified once they are officially part of the stem cell network.

Registering as a stem cell donor is a long-term commitment and matching a patient in need can take days, weeks, months and even years — if ever. The national agency will contact a donor if they are a potential match.

So, you're a match. Now what?

**Step 1** A registered nurse will go through a comprehensive health assessment to make sure the registrant can safely donate.

**Step 2** If approved, the donor is then required to undergo a physical examination and routine medical tests.

**Step 3** Once confirmed as medically eligible, the donor must consent to donation and begin pre-transplant treatments. They will donate stem cells one of two ways: through the peripheral blood or bone marrow.

**Step 4** Stem cells are collected and transferred to the recipient patient.

Alanna Smith



A year ago, Susan Nguyen donated her stem cells to save her brother's life on Halloween day. Her younger brother Bille was diagnosed with T-cell lymphoma.

ings, that roller-coaster ride and the darkness,” said Nguyen. “It just seemed like the right thing to do, to continue.”

Through partnering with other families, Nguyen has found success and heartbreak, with some individuals losing their battles and others receiving a second chance.

Another person fortunate to find a hero was Adrienne San Juan's teenage sister Roshlind Mance, who faced difficult odds in finding a life-saving donor of Filipino descent.

“Our world came crashing down when we found out that only one per cent of Canada's stem cell database is comprised of Filipino donors,” said San Juan. But through tireless advocacy and multiple donor drives in Western Canada, a match was found.

Much like Nguyen, the experience motivated San Juan to continue to raise awareness and ignite action. She is now a territory manager with CBS, organizing swabbing campaigns across Western Canada.

“I still see my sister in those patients. I still put 110 per cent of myself into helping each family find a match,” said San Juan. “It's really heartbreaking because they know that there is a cure for these people, but it's just the fact of finding that one specific person who will be able to help them.”

She thinks non-Caucasian communities aren't represented in the national registry due to lack of awareness and understanding of the procedure, in addition to cultural differences.

on the brink of failure.

The news launched Susan into action, travelling the country and posting on social media to encourage members of the Asian community to get swabbed. She estimates over 1,000 people have signed up since the campaign began.

In the midst of it, Susan was given “the best news ever” — she could save her brother's life.

“It was such a roller-coaster ride,” she said. “Multiple times I went into the dark side and just kind of crawled into a corner and lost hope.”

Even when Bille was given the green light, ill health forced delays for the transplant. Finally, on Halloween day last year, Susan made the donation, and while her brother isn't “out of the woods yet,” he's recovering well.

It would have been easy for her to stop encouraging others to donate after that, but with a strong momentum and an organic movement bubbling she continued to advocate for others to join the registry.

“Anytime I hear somebody who's going through what we did, it just brings back all those horrible feel-



In the Philippines, for example, San Juan said there's nothing like a stem cell registry so many Filipino-Canadians have no idea it exists in Canada. You can also be paid to donate blood in the island nation, whereas there is no financial gain here.

Culturally, she noted, there are also some ethnic groups that believe when they die, everything they have must go with them.

Part of San Juan's role is to break down these barriers and explain how becoming a donor is easy, painless and potentially life-saving for someone in need.

There are three ways to donate stem cells: through peripheral (circulating) blood, umbilical cord blood and bone marrow.

The first option involves a procedure similar to a blood transfusion and the latter involves a short surgery in which stem cells are collected near the back of the pelvic bone.

Cord blood is collected from the placenta and umbilical cord after a healthy baby is born. It's the most viable source, considering the cells are immature and allow for less strict matching.

That helps people who are having difficulties finding a "genetic twin," such as mixed-race and Indigenous patients, explained Dr. Heidi Elmoazzen, director of stem cells for CBS.

In Alberta, all donor stem cell transplants are conducted in Calgary at the Tom Baker Cancer Centre and retrieval of cord blood donations takes place at the Lois Hole Hospital for Women in Edmonton.

Dr. Mona Shafey, lead bone marrow physician with Alberta Health Services, said anywhere between 80 and 100 stem cell transplants are completed each year, and the numbers keep growing with new applications on the horizon, such as treating sickle cell disease.

Both Shafey and Elmoazzen note that attracting donors is key in helping Canada's ethnically diverse population fight a number of diseases, but another important factor is educating registrants on the commitment that accompanies the action of signing up to be a donor.

Elmoazzen said as many as 50 per cent of registered donors who match with a patient don't follow through, further reducing the potential for patients to receive a transplant.

And that, she said, is unacceptable.

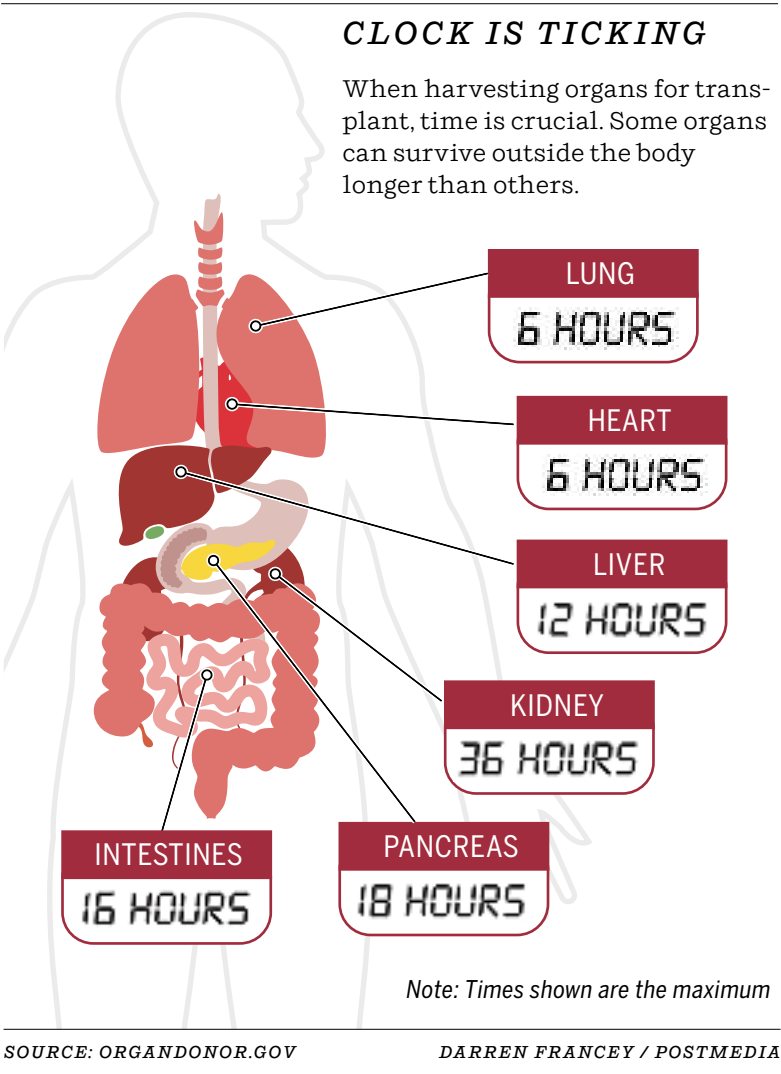
There are about 920 patients currently awaiting a match in Canada, one of which is little Tanner.

While superheroes are a nice distraction for the young boy who undergoes transfusions every three weeks, his mother continues to hope a real hero saves him soon.

For more information about Canada's stem cell registry, visit [www.blood.ca](http://www.blood.ca)  
[alsmith@postmedia.com](mailto:alsmith@postmedia.com)  
[twitter.com/alanna\\_smithh](https://twitter.com/alanna_smithh)



Fort Saskatchewan lung transplant recipient Doug Pearson credits the success he's had since his operation to the strong support he's received from his family, his medical team and his friends. "It had been 20 years since I was able to do anything without coughing." IAN KUCERAK



# BREATHING EASY

Fort Saskatchewan man cycles 122-km race on donated lungs

SHAWN LOGAN

It's said that riding a bike is a breeze, even if one hasn't put foot to pedal for years.

For Fort Saskatchewan senior Doug Pearson, he hoped that same analogy could extend to the basic ins and outs of breathing. It had been years since Pearson had been able to breathe normally due to a lengthy battle with lung disease. But he believed the simple act of taking a breath would again come naturally after receiving a transplant to replace his failing organs.

Despite leading an active life, the 65-year-old had always struggled to catch his breath, often tiring quickly during physical activity. But by 2010, even walking up a flight of stairs was a torturous undertaking. He would ultimately be diagnosed with interstitial pulmonary fibrosis, which causes progressive scarring of lung tissue and is generally irreversible.

His health worsened during a cruise vacation in 2016. Pearson suffered a blood clot that left him nearly unable to breathe, leading to an airlift back home to Alberta.

Like many other people with serious illnesses, he landed on a transplant wait list. Fortuitously for him, however, his blood type and lung size made the act of finding a matching set of lungs a relatively swift process.

A month after Pearson thought he might be taking his final breaths, he got the phone call telling him his surgery was scheduled for the next day.

On Sept. 5, 2016, Pearson got new lungs and a new lease on life.

"It had been 20 years since I was able to do anything without coughing," he recalled from his home in Fort Saskatchewan, northeast of Edmonton.

"It was quite amazing," he said of how he felt with new lungs.

As his body healed and he was able to engage in more physical activity, Pearson reacquainted himself with an old friend he hadn't seen for quite a while.

"I still had my old bike that I got in 1993," said Pearson, who earlier in life had been an avid cyclist, doing the 310-kilometre Golden Triangle trail between Golden and Lake Louise.

So, he started riding. As he became more comfortable riding lon-

ger distances, a friend suggested he give his new lungs a true baptism and enter the gruelling 122-kilometre Gran Fondo ride from Vancouver to Whistler, B.C. — a scenic and challenging route which ascends some 1,900 metres along the Sea to Sky Highway.

In September 2019 — two days after the third anniversary of his life-changing transplant — Pearson joined some 4,500 other cyclists (likely all of whom had their original lungs) at the ride's starting line.

"You start off in Stanley Park and then it's all uphill," Pearson said. "That first 70 kilometres felt pretty light but that last 55 kilometres from Squamish on, I didn't feel very good. I could have quit 10 times over the last 20 kilometres."

But he didn't. Shaking off the pain, the fatigue and pushing his second set of lungs to the limit, Pearson persevered and completed the race in seven hours, 42 minutes and 43 seconds.

He ranked 3,502 of the 3,618 who completed the race.

"I thought there's no way in hell I'm quitting," Pearson said, adding the notion of doing an event like that with a pair of donated lungs still seems surreal.

"Never in my wildest dreams did I think I could do this."

Long-term survival following a lung transplant is far from guaranteed. According to statistics from the Canadian Institute for Health Information, some 86 per cent of lung transplant patients in 2010 survived for at least one year after the surgery. The odds drop from there, with 75.5 per cent living another three years and 65.5 per cent of patients during the same period making it to five years.

For Pearson, who has returned to work part-time at a local pro shop, he's already planning his next challenge — the 152-kilometre Kootenay Rockies Gran Fondo in Cranbrook next summer.

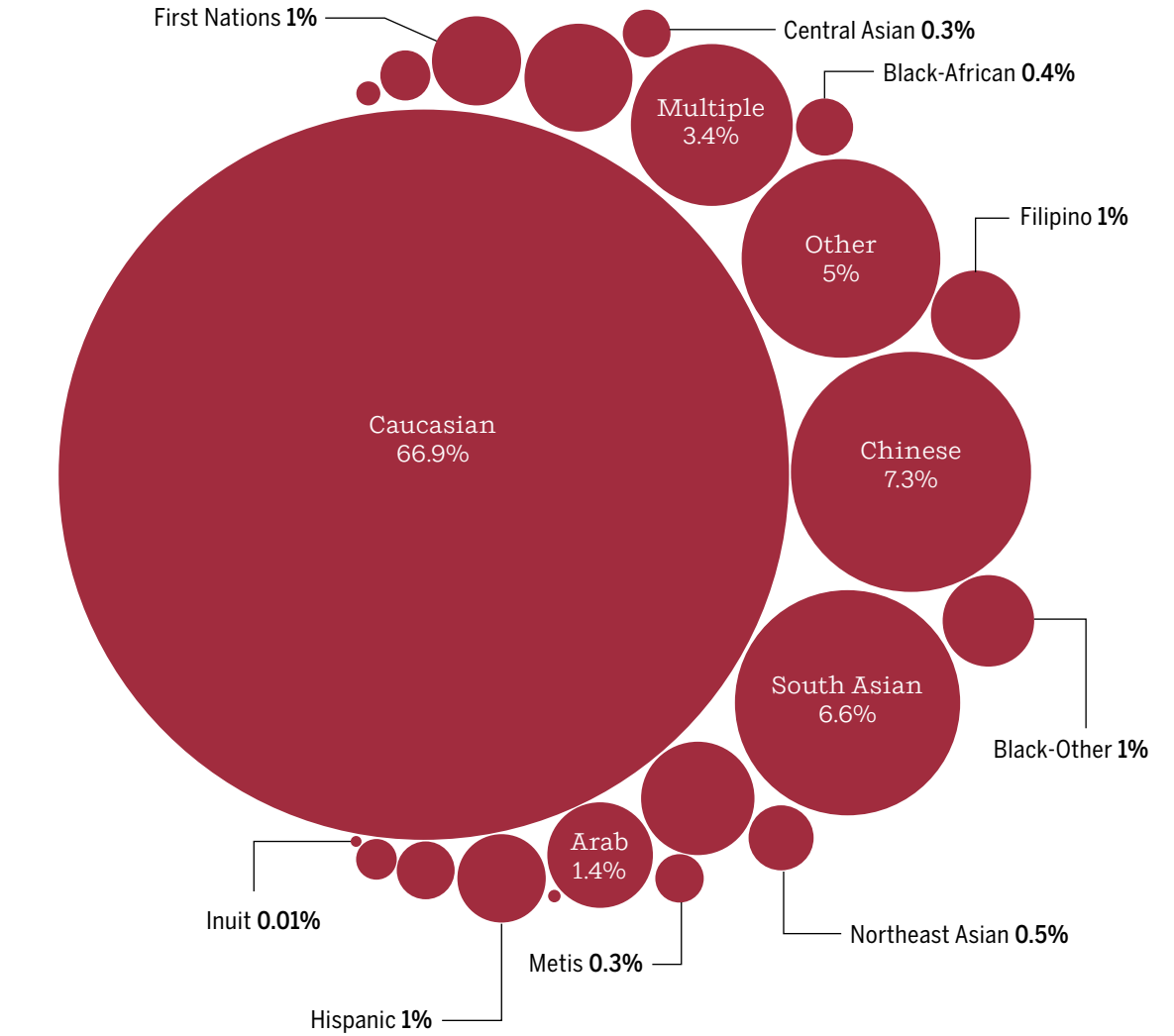
And he has some positive advice for those who are in critical need of organs, especially when they think about future plans and personal possessions.

"If I were ever to talk to anybody going in for a transplant, I would say, 'Don't give anything away,'" he said. "You've got to keep that stuff for when you get better."

[slogan@postmedia.com](mailto:slogan@postmedia.com)

## ETHNIC MAKEUP OF STEM CELL REGISTRY

There were 454,482 people on Canada's stem cell registry, as of September, 2019. Although many people put their names forward, only about half follow through with the commitment, according to Canadian Blood Services. Two-thirds of the registrants are Caucasian, with First Nations, Metis and Inuit accounting for only 1.3%.



SOURCE: CANADIAN BLOOD SERVICES

DARREN FRANCEY / POSTMEDIA



# What you can do to help save a life

Saving the life of a fellow Canadian can be as easy as checking a box online or saying yes to being an organ donor when you renew your driver's licence. But that's just the beginning.

### DECEASED DONATIONS

In Alberta, individuals over the age of 18 can register their intent to become an organ or tissue donor when they die by using the Alberta Organ and Tissue Donation Registry. (Go to my-health.alberta.ca online and search organ donation registry.) As well, agents and provincial registries are required to ask the donor question when clients are renewing a driver's licence or identification card.

For those who have Alberta Health Cards issued prior to 2018, the back of the card can be signed (with a witness) to declare their intention to donate.

The Alberta registry has been integrated into the province's health-care system through the use of donor co-ordinators. If a person has declared his or her intent to donate and is in a position to be considered for organ or tissue donation, a co-ordinator will discuss it with family members, who ultimately make the final decision.

Each deceased donor can provide up to eight organs (both lungs, both kidneys, liver, heart, pancreas, intestines), while donated tissues can benefit up to 75 individuals.

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The vast majority of living organ donors spares one of their two functioning kidneys to a person in need, though living liver donations also occur to a lesser extent.

In most cases, family members or acquaintances donate a living organ if they're healthy enough to safely act as a donor. Once a viable donor is found, transplant programs in both Calgary and Edmonton perform the surgeries for kidneys, while live liver transplants are only performed in Edmonton.

There's been a rise in so-called altruistic donors, who are willing to share their organs with a stranger. Both the Kidney Foundation of Canada and Canadian Blood Services can advise prospective living donors on where to turn, while Alberta Health can connect donors to local living donor programs.

Canadian Blood Services also operates the Kidney Paired Donation Program, an interprovincial initiative that maintains prospective donors in a registry if they aren't a compatible match for their intended recipient. Since January 2009, some 500 living donors across Canada have entered the KPD program, including 90 anonymous donors who joined the program without a specific recipient in mind. Non-directed, anonymous donations are responsible for more than two-thirds of the transplants in the KPD program, and all patients with a match have received a transplant in less than a year.

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**Details about Green Shirt Day** and Logan Boulet are at greenshirtday.ca.

### STEM-CELL DONATIONS

Stem-cell transplants replace a patient's unhealthy stem cells with a donor's healthy ones, and can be used to treat cancers and other diseases. The three sources of stem cells are from bone marrow, peripheral (circulating) blood and umbilical cord blood.

Prior to any donation, the donor will undergo a comprehensive health assessment before undergoing the procedure. Peripheral blood stem-cell donation only requires blood to be drawn from a needle in hospital following five days of under-the-skin injections to boost the number of blood cells in the bloodstream.

Bone marrow donations are performed under anesthesia, with hollow needles used to withdraw stem cells from bone marrow in the back of pelvic bones. The procedure lasts between 45 to 90 minutes and the marrow replenishes itself in four to six weeks.

Those who wish to become a stem cell donor can call Canadian Blood Services at 1-888-2-DONATE (1-888-236-6283) or by visiting the agency's website at blood.ca.

Shawn Logan



Mylene Malabanan, left, and Kathy Shirley, right, were friends and colleagues at Sobeys in Calgary when Shirley volunteered to be a liver donor for Malabanan's daughter, Ica, centre. "This is my blood type, if I can help." Shirley told her friend after learning of Ica's liver cancer diagnosis. MIKE DREW

## GIFTS OF LIFE: PART 3, CONTINUED

# 'THERE WASN'T ANY FEAR'

Donors say they didn't hesitate to provide partial liver transplants

YOLANDE COLE

On the recent one-year mark of a life-saving surgery, 12-year-old Ica Malabanan sent Kathy Shirley a gift of a watch, to recognize the amount of time Shirley had devoted from her life last fall to give the child what doctors said she urgently needed: a liver transplant.

The morning of October 22, 2018, both Shirley and Ica went into surgery in Edmonton — Ica for a procedure that would last close to 10 hours. She remained in Edmonton for three months during her recovery, while it took Shirley two-and-a-half months before she was able to return to work.

But the recovery time was all worth it when Shirley now sees Ica smiling and healthy.

"The day I went and said goodbye (in the hospital), it was heart-breaking," Shirley said. "She was in a little ball and there were tubes. That's what I remember, and seeing (her) now — it's awesome."

When Shirley volunteered to be a liver donor, she hadn't even met the girl yet. But she and Ica's mother, Mylene Malabanan, were friends and colleagues at Sobeys. Before Sobeys, the pair had coincidentally been co-workers at two other workplaces — much to the surprise of both of them, as they kept encountering each other on the job.

Mylene said Shirley would often ask how she was doing, and how her kids were. But one day when she asked the question in a break room, Mylene couldn't hide her emotions. Ica was not doing well and would need a transplant. Doctors advised it was the only treatment option for Ica after her liver cancer returned for a second time, following her first diagnosis at nine years of age.

Shirley said her response to her friend was, "This is my blood type, if I can help."

It turned out she was needed, as Ica's mother and other immediate



Jennifer Vo donated a piece of her liver to daughter Taya, front right, in 2017. The family, including dad Trieu and Taya's sister, Taryn, stayed in Edmonton for three months after the transplant. DARREN MAKOWICHUK

family members didn't share the same blood type, and the transplant needed to occur as soon as possible. And when Mylene went back to Shirley to talk about a donation, her co-worker didn't hesitate to volunteer to give up part of her liver to save Ica.

"There wasn't any fear, even being wheeled into the surgery room," Shirley said. "I had my mind made up. And obviously (it was) worth it."

The donor has now formed a much stronger friendship with her co-worker, and a special bond with Ica. While the Grade 8 student still has frequent medical appointments, and has to take daily anti-rejection medications, she has returned to a normal life involving school, singing and dancing.

According to the Canadian Liver Foundation, the long-term success rate of transplantation for adults and children in Canada is over 80 per cent, and most patients return to a good quality of life within

three to six months after surgery.

In 2018, Alberta Health Services statistics indicate 12 living donor liver transplants were performed in Edmonton. Liver transplants from living donors are far less common than kidney transplants from living donors.

However, the need is great. There are more than 100 liver diseases caused by a variety of factors, and one in four Canadians may be affected by these diseases, with ages of patients ranging from newborns to seniors. Biliary atresia is the leading cause of liver failure in children.

Taya Vo, 12, was diagnosed with biliary atresia at 11 weeks of age, after her parents took her to the hospital with jaundice. She then underwent surgery to connect her small intestine directly to her liver.

But her parents, Jennifer and Trieu, knew the surgery would only be a temporary fix. At 10 years of age, Taya was placed on the liver transplant waiting list because she

was suffering from hepatopulmonary syndrome, which affects the lungs of people with advanced liver disease.

"Her oxygen level was sitting in the low 70s, which for us, if we were sitting at the low 70s, I don't know if we could function," said Jennifer.

"So for a while, her body was kind of adjusting, but it's really low oxygen, and that was the reason why she had the transplant."

As soon as Taya was placed on the transplant waiting list, Jennifer began undergoing various tests to see if she could donate part of her liver to her daughter.

For living transplants, donors are matched with recipients based on compatible liver size and blood type. Scans and biopsies and other tests confirmed that mother and daughter were a match, and both went into surgery on Dec. 12, 2017, just a few months after Taya went on the transplant waiting list in August.

Jennifer described the transplant as a "big, big production" involving two teams and medical professionals, including a pediatric anesthesiologist and pediatric plastic surgeon.

For Taya, the procedure lasted 12 hours, while Jennifer was in the operating room for just over six hours.

Going into the procedure, "I was really nervous," Taya recalled. "I was scared."

The transplant also involved the entire Calgary family staying in Edmonton for three months, with both parents taking leaves from work and older sister Taryn taking a break from her school.

"I think having her sister there got her better a lot quicker," Jennifer said.

Taya agreed, noting her older sister wheeled her oxygen tank around for her in the hospital, and played video games with her during recovery. Because the hospitals where they each had their surgeries were attached, Jennifer could roll down the hall in a wheelchair to visit her daughter.

While a new liver for Taya brought the family relief, they noted there are still lots of "ups and downs and bumps along the way," including the ever-present worry of potential rejection of the new liver.

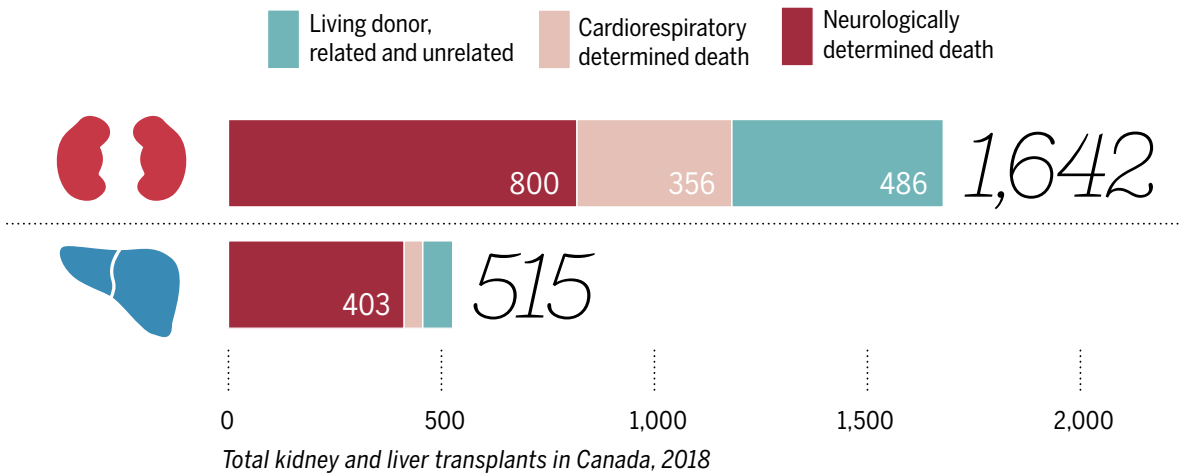
Following the surgery, Taya took 11 daily medications; a number now reduced to four daily anti-rejection meds. Since the procedure, her parents say she has had a couple of instances where her body appeared to be rejecting her liver and doctors had to adjust her medications.

Jennifer said it took about two months for her to recover from her surgery, in which doctors removed a portion of her liver. But she didn't even think twice about undergoing such a major procedure.

"Everybody's like, 'Oh that's an amazing thing you would do,' but at the same time, who wouldn't? Like honestly, who wouldn't do it?"

## COMPARING KIDNEY AND LIVER TRANSPLANTS

Proportionally, there are more living donors for kidney than for liver transplants. For both procedures, the long-term survival rate is above 80% — even higher when the donor is living. The health risks to living donors, meanwhile, is minimal.



SOURCE: CIHI, KIDNEY FOUNDATION OF CANADA, CANADIAN LIVER FOUNDATION

DARREN FRANCEY / POSTMEDIA



GIFTS OF LIFE

PART 4 OF 5

- Nov. 2: Social media and marketing: A new era of organ donations
- Nov. 9: Alberta's centre of transplant excellence
- Nov. 16: After transplantation: New leases on life
- Nov. 23: How organ donation works in Alberta
- Nov. 30: Opt in, opt out: How to better meet a critical need

For more information, stories and videos go to [calgaryherald.com](http://calgaryherald.com).

Bruce and Susan McKenzie stand by pictures of their late daughter Marit McKenzie at the end of the annual Marit Cup, in 2016 at WinSport. POSTMEDIA PHOTOS



# YOUNG HEROES SAVE LIVES

Marit McKenzie was just 17 when she lost her life. Her donated organs were vital to others.

SHAWN LOGAN

Tanner Fitzpatrick and Mark Klassen live more than 6,000 kilometres apart, on opposite sides of the country, but both proudly sport tattoos that honour the sacrifice of a young Calgary woman who decided as a teenager to become an organ donor.

Marit McKenzie was 17 when she made the life-saving decision to sign her donor card, motivated to do so because best friend Paige Thakker had been the recipient of a donated liver while still an infant.

Marit wouldn't have had any idea just how quickly that choice would become critical. Just months after making that decision in January 2013, Marit suffered a pulmonary embolism followed by a quartet of cardiac arrests that left her with no chance of recovery.

"That night, when Marit passed away, the doctor was so brave," her father, Bruce McKenzie, recalled. "His first words were, 'I'm very sorry to tell you this, but Marit is brain-dead and will not recover.' And his very next words were, 'Would you consider organ donation?'"

Because Marit had already told mother Susan about her decision, the choice — though heartbreaking — wasn't a difficult one.

It's a possibility few parents ever want to consider: Should one of their children suffer an untimely death, could their organs and tissue be used to help others? In Marit's case, her own passion about the issue made the process smoother. But organ donation advocates say families don't always get clarity regarding their loved ones' wishes before tragedy happens, particularly when it comes to children.

Ultimately, Marit would share not only her heart, but both kidneys and her liver, all of which were successfully transplanted. She also donated her corneas, granting the gift of sight to two other people, along with donating tendons and bone tissue.

As Bruce and Susan spent their final care with Marit in the intensive care unit, little did they know the wheels were already in motion to ensure her dying gift made a difference.

In Burin, NL (affectionately nicknamed "The Boot" by its 2,300 or so residents), the Fitzpatrick family received a call they'd been waiting for since their 14-year-old son Tanner was placed on a heart transplant list just six days before Marit's death.

"At that time, we didn't know Tanner was being notified a heart was available and he was getting on a plane from Newfoundland to Toronto," Bruce said.

Thanks to Marit's gift, an anonymous one at the time, Tanner's life changed almost immediately and



At that time, we didn't know Tanner was being notified a heart was available and he was getting on a plane from Newfoundland to Toronto.

after a four-month hospital stay he returned home with the Calgary girl's strong heart beating defiantly in his chest.

Meanwhile, Calgarian Mark Klassen received a kidney and a pancreas from Marit, and like Tanner Fitzpatrick found a way to connect with the McKenzies, through sleuthing, curiosity and help from an anonymous letter sent through donor agencies.

Both men would later become involved in a hockey tournament started by Marit's former school, the Calgary Christian School, dubbed the Marit Cup. Three years



Above left is Tanner Fitzpatrick, then 17, at one of the Marit Cup tournaments; he received the heart of Marit McKenzie, who died in 2013 from a pulmonary embolism. Above right, Mark Klassen — who received Marit's kidney and pancreas — shows the tattoo he got in commemoration of the transplanted organs.

after his successful transplant surgery, Klassen would drop the puck in the fourth edition of the tourney while Fitzpatrick actually donned his goalie pads to play in the event two years ago.

Both also sport tattoos commemorating Marit's sacrifice, with Klassen's tattoo containing the initials M.M. and the date of his transplant, and Fitzpatrick commemorating his transplant day over his donated heart.

That generosity of spirit — of young adults deciding to bestow an ultimate gift on others — was also reflected last year in the after-

math of the devastating Humboldt Broncos bus crash. One of the 16 people who died in the crash, Logan Boulet, has become a beacon for the cause of organ and tissue donation.

The young hockey player's decision to become a donor was a tribute to his former mentor and fitness coach Ric Suggitt, whose death from a cerebral hemorrhage in June 2017 deeply affected Logan. Upon learning his friend and mentor was able to save six lives via organ donation, Logan decided that he would sign his organ donor card on his 21st birthday, which occurred a little more than a month before his death.

His father Toby Boulet said Logan made the pledge to 13-year-old McLaren Paulsen — the son of his billet family in Saskatchewan — a few days before his birthday.

"Logan said, 'I'm going to sign my organ card in honour of Ric Suggitt,' and he said, his exact words were, 'If Ric can save six lives, so can I,'" Toby said.

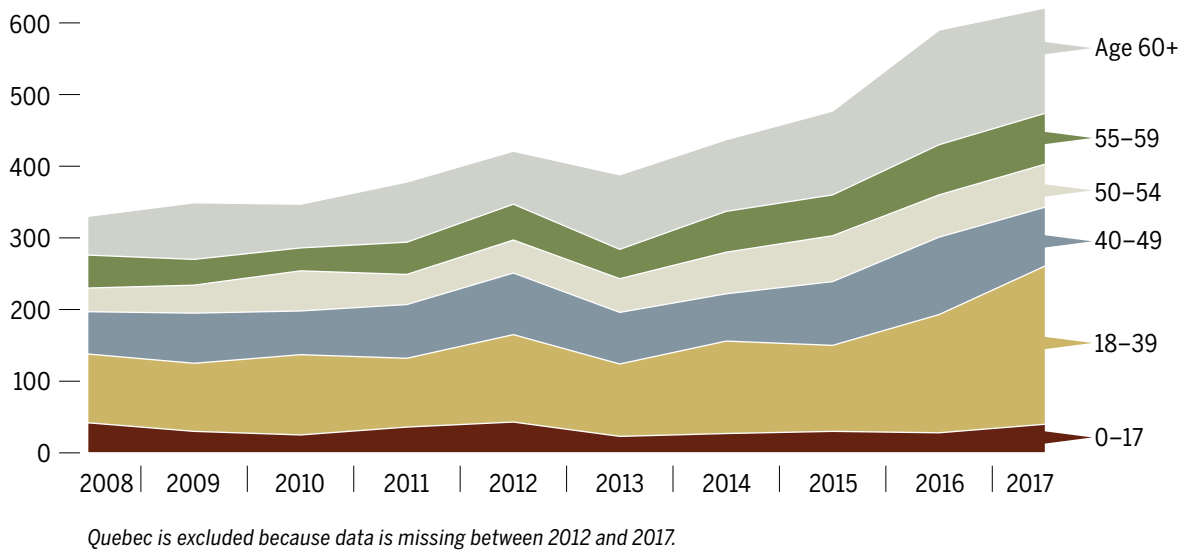
"People who know Logan, no one was surprised. If you don't know Logan, they're surprised. They're thinking, 'Well you're 21, what are you talking about that for?'"

But Logan's message is vital, Toby said: "He's not talking about death, he's talking about life."

As news of Logan's final gift began to spread — and as Canadians mourned the deaths of the young athletes and other Bronco family members killed on a Saskatchewan highway — something remarkable happened.

## AGE OF DECEASED ORGAN DONORS, CANADA

People aged 18 to 39 and 60-plus donate more than all other age groups combined.



Quebec is excluded because data is missing between 2012 and 2017.

SOURCE: CANADIAN INSTITUTE FOR HEALTH INFORMATION

DARREN FRANCEY / POSTMEDIA





Bernadine and Toby Boulet, whose son Logan donated six of his organs after the Humboldt Broncos bus crash took his life, now advocate for Green Shirt Day to promote organ donations. *DARREN MAKOWICHUK*

From coast to coast, Canadians began signing their donor cards at a rate seldom seen by officials at organ and tissue donation agencies.

It was soon dubbed the Logan Boulet Effect, and in the days following the April 6 crash, some 100,000 people had registered as donors. In April of this year, which marked the first Green Shirt Day held in honour of Logan's sacrifice, at least another 60,000 Canadians signed up — about three times more than the average monthly number.

Unlike the McKenzie family, the Boulets haven't yet made any contact with the

*I would love to meet the person who has Logan's heart and to listen to his heart again.*

recipients of his organs — his lungs, liver, one of his kidneys, his corneas and his heart, which mom Bernadine listened to during many of Logan's final 27 hours.

"I would love to meet them. I would love to meet the person who has Logan's heart and to listen to his heart again," Bernadine said, fighting back emotions.

"When we were in the hospital, one of the things I really liked to do was put my head on his chest and just listen to his heartbeat. So, I would love to do that again."

While individual provinces differ a bit when it comes to regulations, families of organ donors are able to write letters to transplant recipients through various agencies, although the information about the donor must be non-specific.

Recipients can then choose to respond, through the same agencies, with similarly vague information.

In spite of those barriers, both Tanner Fitzpatrick and Mark Klassen were able to deduce on their own that Marit was the one who gave them their second chances at life.

And for father Bruce, making those connections has been an important part of the healing process of losing his daughter.

"Susan and I feel blessed that we were able to meet some of the recipients," he said.

"It helps build a sense of closure and reality. Because of that, we know our daughter has had an impact."

## What you can do to help save a life

Saving the life of a fellow Canadian can be as easy as checking a box online or saying yes to being an organ donor when you renew your driver's licence. But that's just the beginning.

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*Shawn Logan*

# A DONOR'S JOURNEY

It all starts when the decision to donate is made, but that's only the beginning of an involved process, *Shawn Logan* writes.

A critical window opens for only a short period of time when a family makes the life-changing decision to allow a dying loved one to become an organ and tissue donor.

The window can open during only two types of deaths, which allow for doctors to harvest vital organs and tissue that can be used to save or improve the lives of others. The first death is one in which the brain stops functioning (neurological death), but other vital functions remain operative. The second is cardio-circulatory death, in which life is not sustainable without a ventilator.

Dr. Andreas Kramer, medical director of the Southern Alberta Organ and Tissue Donation Program in Calgary, said once medical staff in an intensive care unit receive consent from family members following these diagnoses, a Canada-wide network gets to work to connect patients in greatest need with any viable organs or tissue that can potentially be transplanted.

"There is lots of organ-sharing that occurs across provincial borders in Canada, in order to ensure that the person in greatest need is the one that gets the organ next," he said.

"Most of this kind of organization and administration of where the organ goes, that all happens while the organ donor is in an intensive care unit on life support," Kramer said. "It occurs between the time of consent that's obtained from the family and the donor going to the operating room to have the organs removed."

That window is usually 24 to 36 hours, Kramer said, but can extend to as much as 48 to 72 hours in some cases.

Depending on the health of the donor and the type of death, as many as eight organs can be transplanted: two lungs, two kidneys, heart, liver, pancreas and intestines.

When it comes to tissue, which must be removed within 12 to 24 hours after death, the potentially life-changing gifts include corneas, heart valves, skin, bone, tendons and amniotic tissue, which can benefit as many as 75 people.

Kramer said once a family agrees to organ donation, medical personnel do everything they can to ensure viability of the organs to give them the best chance for successful transplantation.

"While we're caring for an organ donor on life support, we're trying to optimize the organ function as much as possible," he said. "And then, there's some very careful decision making made around whether the organ can actually be transplanted or not."

Every harvested organ is on the clock once it's removed, so time is of the essence in ensuring the recipient is ready for transplant as soon as possible. Hearts and intestines need to be transplanted within four to six hours while kidneys can remain viable for up to 12 to 24 hours after removal.

In 2018, some 532 viable organs were procured from patients with a neurological death, with another 230 obtained via cardiorespiratory death.

In Alberta, those numbers were 50 and 21, respectively.

Once a patient has an organ successfully transplanted, the work isn't over.

Anti-rejection medication is critical for those who've had a transplant to ensure the body's built-in protection mechanisms don't attack the new organ. And they can expect years of follow-up with doctors to monitor both the organ's and the patient's health.

In terms of extending the life of organ recipients, in most cases between 80 to 90 per cent of patients survive at least five years; lung transplants see seven out of 10 reach the five-year mark, according to the Canadian Institute for Health Information.

For kidney recipients, both suitability and longevity of the organ are significantly increased if the kidney came from a living donor.



Dr. Mauricio Monroy-Cuadros

When it comes to living donors, kidneys account for the vast majority of such procedures, although living liver transplants also occur. (There have also been rare instances of living lung donations.)

Dr. Mauricio Monroy-Cuadros, a transplant surgeon and medical director of Calgary's living donor program, said kidney patients represent about eight in 10 of those needing organ transplants in Canada, and traditionally some are lucky enough to have a friend or acquaintance who's a match for them and is willing to spare a kidney.

However, more and more people are coming forward who have no relation to the patient, which importantly boosts the potential to save lives.

"Usually, there is somebody in the family — or a friend or relative — that is willing to donate a kidney, and then you get a transplant from that person," Monroy-Cuadros said.

"And there is a second way within the living donors, which is a person we call an altruistic donor or non-direct donor. They come forward to the program and say, 'I consider myself healthy and blessed because I have two functional kidneys and I want to help somebody.'"

Of the 38 to 45 kidney transplants Monroy-Cuadros performs annually, about 10 to 15 represent these altruistic donors — strangers who want to help someone in need with a life-giving gift.

Before someone can become a living donor, candidates undergo a battery of tests including physical, medical and mental health assessments.

He said about half of altruistic donors will actually make it through the testing and be approved to continue in the process.

Once a prospective donor is given the green light, it's simply a matter of scheduling a date for surgery.

On the day of the surgery, both the donor and recipient are placed in nearby operating suites. The operation to remove the kidney itself generally takes four to five hours and it will be transplanted into the patient within 15 to 30 minutes, Monroy-Cuadros said.

The success rate of the surgery, in normal conditions, is around 99 per cent."



The window for transplanting organs from a deceased individual can range from four to 24 hours, depending on the organ. *SEAN GALLUP/GETTY IMAGES*



GIFTS  
OF LIFE

PART 5 OF 5

**Nov. 2:** Social media and marketing: A new era of organ donations  
**Nov. 9:** Alberta's centre of transplant excellence  
**Nov. 16:** After transplantation: New leases on life  
**Nov. 23:** How organ donation works in Alberta  
**Nov. 30:** Opt in, opt out: How to better meet a critical need

For more information, stories and videos go to **calgaryherald.com**.



Spain has had a presumed consent model for deceased organ donation for 40 years. Its 47 donors per million population are more than double Canada's rate of around 22 per million. "Presumed consent is the beginning of a discussion," said Jake Kuiken, whose wife is "waiting to die." *GETTY IMAGES*

# OPT IN OR OPT OUT?

Will Alberta follow Nova Scotia's lead with opt out legislation for organ donations?

SHAWN LOGAN

In the spring, Calgary grandmother Keenie Kuiken saw her last chance at reversing a disease that is slowly destroying her liver erased forever.

Last year, Keenie was one of 72 Albertans on a waiting list for a liver transplant. It's a list where she had lingered since the fall of 2016 after receiving a diagnosis of primary biliary cholangitis, while hoping and praying for the phone call that would tell her a healthy replacement organ was available.

Both she and her devoted husband Jake kept their bags packed, ready to travel at a moment's notice if a donor liver became available. The phone never rang.

Earlier this year, Keenie, who will turn 72 in December, saw her name removed from the national waiting list due to her deteriorating health. And now, her wait has become a much darker one.

"She's waiting to die," said Jake, who spent years battling with health officials to even get his wife's name pencilled onto the transplant waiting list, only to see it removed early this year.

And it's his beloved Keenie's struggles to secure one of the small handful of donor livers that become available every year that has made Jake a staunch advocate for Canada to adopt what's called a presumed consent, or opt out, model of organ donation.

The model places the onus of opting out from organ donation on the families of those deemed eligible to donate organs after death.

It's an idea that has taken root in dozens of countries, particularly in Europe and South America, some of which boast some of the most robust deceased donor rates globally.

Spain, which has had a presumed consent model for deceased organ donation for 40 years, has long been recognized as the top performer globally, with its 47 donors per million population, more than doubling Canada's existing rate of around 22 per million.

Out of the top 15 countries for organ donation (of which Canada ranks 15th), nine have either implicit or explicit presumed consent models.

"Presumed consent is the beginning of a discussion," said Jake, a retired social work professor at the University of Calgary.

"The debate we should have is about saving lives, and how we should do it. You're going to donate no matter what: it's either to the worms or to the fire," he said, referring to burial and cremation.

When someone dies, as many as eight potentially life-saving organs can be harvested, along with vital tissue that can improve the lives of up to 75 people. But given the narrow medical circumstances that permit organs to be recovered, only about one in 100 organ donors will actually contribute to the transplant pool.

Around the same time Keenie was being informed that she was being de-listed as a transplant candidate, the government of Nova Scotia was passing legislation that

would make the province the first in Canada to establish a presumed consent, or opt-out model, for organ donation.

Bill 133, the Human Organ and Tissue Donation Act, was passed unanimously in April by legislators in the Maritime province, but it's not expected to be proclaimed as law until 12 to 18 months of groundwork is done to allow time for planning, implementation and public education.

The bill was championed by Nova Scotia Premier Stephen McNeil, who said while he doesn't have any family connections to those in desperate need of an organ transplant, he has met more than enough people on these waiting lists to know more can be done to help.

"In this province, we have been burying hope. This bill will change lives," he said. "It's really reverse onus. If you don't want to be a donor, you don't have to be. But I believe in the core of people. Why wouldn't you want to save a life?"

McNeil said just changing the equation isn't enough, which is why the province is taking time to consult with the public, to train and educate medical staff and to ensure the infrastructure is in place to take advantage of the new reality.

Once the appropriate systems are in place, McNeil said it will be



MLA Matt Jones

a small but powerful change in the organ donation chain at health-care facilities.

"Moving forward changes the question. You move from the question, 'Is your loved one an organ donor?' to 'Your loved one is an organ donor, will you continue?'" he said. "So far, it's been very positive. We were told we should get some negative feedback, but there's been very little."

Dr. Andreas Kramer, medical director of the Southern Alberta Organ and Tissue Donation Program in Calgary, said while many people believe presumed consent models will generally increase the supply of transplant-ready organs, the conversation isn't necessarily that simple.

"Obviously, changing your legislation to presumed consent is going to have no impact on the number of patients with brain in-

juries; it'll have no impact on the outcomes of those patients with brain injuries," he said.

"It shouldn't have any impact on health-care professionals' identification and referral of potential organ donors," he added. "So, if it's going to have an impact on organ donation rates, it really would happen by increasing consent rates, and ... I'm not sure people who really advocate strongly for presumed consent have very good evidence that it has an effect on the consent rate."

He noted many jurisdictions that employ presumed consent models use more of a "soft presumed consent" system, in which families are still consulted that in many ways is no different than the opt-in system that currently exists in most Canadian provinces.

"We don't assume that because they maybe haven't registered, that they automatically wouldn't want to be a donor," Kramer said. "Consequently, we approach the family and we ask the family what they think their loved one might have wanted. And, of course, if the family thinks they would have wanted (to be a donor), then we go ahead at that point and obtain consent."

Earlier this month, Alberta dipped a first tentative toe into the presumed consent waters af-

ter Calgary UCP MLA Matt Jones tabled Bill 205, a private member's bill which, if passed, would come into effect on Jan. 1, 2022.

Jones said it's a debate long overdue in Alberta given its success around the world, and it could have an immediate impact, saving or improving the lives of hundreds of Albertans annually who, like Keenie, find themselves on a waiting list praying for an organ to come available.

"This is not a new concept. We have examples of this all around the world," said the first-term MLA, who in crafting the bill met with Jake Kuiken and others who've either been the beneficiaries of, or who are in need of, organ transplants.

"This is an opportunity to address something that is a life-and-death issue," he said.

Under the proposed legislation, residents who have lived in Alberta for at least a year would be presumed to have consented to having their organs donated for transplant if they hadn't previously indicated their preference through the province's organ donation registry. However, those under 18 would be ineligible, as would those deemed by medical staff to be unable to make an informed decision.

Ultimately, family of the deceased would still have the right to opt out of the program, as is currently the case. As well, Alberta residents would be able to opt in or out of the registry at any time online.

Jones said he's hopeful his bill will receive enough support that it will be approved into law by the end of the fall legislative session. From there, officials will use the next two years to ensure staff and procedures are in place to ensure the bill's goals are fully realized, while also providing critical public education about the issue.

Alberta Health Minister Tyler Shandro said he's interested in seeing the outcomes of both Jones' private members bill and Nova Scotia's experience, but he hasn't yet made up his own mind.

"Presumed consent is not part of my department's current plans, but I'll respect the views of my colleagues. If the House passes a bill, I'll work to implement it," he said in a statement.

"Organ donation is an intensely personal decision for families, and it's essential that we maintain confidence in the way donation works," he said. "Presumed consent could help increase donations, but it could also raise objections from people who might feel coerced."

Regardless of the outcome of his colleague's motion, Shandro said Alberta needs to get better at optimizing its rate of organ and tissue donation.

"We all want to increase our donor rate. We're doing better in the past few years but we need to do more; the rates in B.C. and Ontario are much higher," he said.

"I'll continue to support AHS and the donor program in taking a range of steps to increase donation."

## Information about being an organ donor

Saving the life of a fellow Canadian can be as easy as checking a box online or saying yes to being an organ donor when you renew your driver's licence. But that's just the beginning.

**DECEASED DONATIONS**

In Alberta, individuals over the age of 18 can register their intent to become an organ or tissue donor when they die by using the Alberta Organ and Tissue Donation Registry. (Go to my-health.alberta.ca online and search organ donation registry.) As well, agents and provincial registries are required to ask the donor question when clients are renewing a driver's licence or identification card.

For those who have Alberta Health Cards issued prior to 2018, the back of the card can be signed (with a witness) to declare their intention to donate.

The Alberta registry has been integrated into the province's health-care system through the use of donor co-ordinators. If a person has declared their intent to donate and is in a position to be considered for organ or tissue donation, a co-ordinator will discuss it with family members, who ultimately make the final decision.

Each deceased donor can provide up to eight organs (both lungs, both kidneys, liver, heart, pancreas, intestines), while donated tissues can benefit up to 75 individuals.

**LIVING DONATIONS**

The vast majority of living organ donors spares one of their two functioning kidneys to a person in need, though living liver donations also occur to a lesser extent.

In most cases, family members or acquaintances donate a living organ if they're healthy enough to safely act as a donor. Once a viable donor is found, transplant programs in both Calgary and Edmonton perform the surgeries for kidneys, while live liver transplants are only performed in Edmonton.

There's also been a rise in so-called altruistic donors, who are willing to share their organs with a stranger. Both the Kidney Foundation of Canada and Canadian Blood Services can advise prospective living donors on where to turn, while Alberta Health can connect donors to local living donor programs.

Canadian Blood Services also operates the Kidney Paired Donation Program, an interprovincial initiative that maintains prospective donors in a registry if they aren't a compatible match for their intended recipient. Since January 2009, 500 living donors across Canada have entered the KPD program, including 90 anonymous donors who joined the program without a specific recipient designated. Non-directed, anonymous donations are responsible for more than two-thirds of the transplants in the KPD program, and all patients with a match have received a transplant in less than a year.

**The Living Donor Services Program — Edmonton:** 780-407-8698  
Toll-free: 1-866-253-6833  
Email: livingdonors@ahs.ca  
**Southern Alberta Transplant Program — Calgary:** 403-944-463  
**More information on kidney health**

**is available from the Kidney Foundation of Canada:** www.kidney.ca; 780-451-6900 or 403-255-6108.

**More information on liver health is available from the Canadian Liver Foundation:** www.liver.ca; 403-276-3390 or 1-800-563-5483.

**Details about Green Shirt Day** and Logan Boulet are at greenshirtday.ca.

**STEM-CELL DONATIONS**

Stem-cell transplants replace a patient's unhealthy stem cells with a donor's healthy ones, and can be used to treat cancers and other diseases. The three sources of stem cells are from bone marrow, peripheral (circulating) blood and umbilical cord blood.

Prior to any donation, the donor will undergo a comprehensive health assessment before undergoing the procedure. Peripheral blood stem-cell donation only requires blood to be drawn from a needle in hospital following five days of under-the-skin injections to boost the number of blood cells in the bloodstream.

Bone marrow donations are performed under anesthesia, with hollow needles used to withdraw stem cells from bone marrow in the back of pelvic bones. The procedure lasts between 45 to 90 minutes and the marrow replenishes itself in four to six weeks. Those who wish to become a stem cell donor can call Canadian Blood Services at 1-888-2-DONATE (1-888-236-6283) or visit the agency's website at blood.ca.

Shawn Logan



GIFTS OF LIFE, CONTINUED

30 days,  
30 faces

The need for organ donations is great. While 2,800 organ transplants occurred last year across the country, another 4,500 Canadians were left waiting for a match. At the same time, 643 people, including 46 in Alberta, died or were removed from those waiting lists. Throughout this month, Postmedia daily newspapers in Calgary and Edmonton have shared stories of some of those people waiting for organs or stem cells and of the generous souls who donate. The need for an organ can impact anyone and, at the same time, anyone can decide they want to provide a fellow human being with the gift of life. Here are some of the people who have given, who have received and who still wait.



**FREDA AINLEY**  
Marked the 45th anniversary of her kidney transplant in 2017.



**LOGAN BOULET**  
Expressed his desire to be an organ donor while still a teen.



**BERNADINE AND TOBY BOULET** Organ donor advocates, who agreed to donate their son's organs after his tragic death.



**DREW BRABBINS**  
Received a lung transplant this month after years of waiting.



**CHRIS CHARLES**  
Edmonton father who needs a kidney transplant.



**SEAN DELANEY**  
Edmonton transplant advocate and kidney transplant recipient, waiting for a second transplant.



**TANNER FITZPATRICK**  
A teenager who received the heart of Marit McKenzie.



**RICK GALLOWAY**  
A grain farmer who received a lung transplant.



**MARK KLASSEN** A Calgarian who received a kidney and pancreas from Marit McKenzie.



**KENDRA LEE-RANKIN**  
St. Albert woman who has undergone surgeries since birth and awaits a heart transplant.



**ICA MALABANA** A 12-year-old Calgary girl who received a live liver transplant from her mom's friend at work.  
**KATHY SHIRLEY** The friend who donated part of her liver to Ica.



**MARIT MCKENZIE**  
Calgary woman who expressed her desire to be an organ donor before her death at 18.



**SUSAN AND BRUCE MCKENZIE** They gave permission for their daughter Marit's organs to be donated in 2013.



**BILLE NGUYEN**  
Received a life-saving stem cell transplant from his sister.



**SUSAN NGUYEN**  
Donated stem cells to save her brother's life.



**TANNER MCLEOD**  
A five-year-old who needs a stem cell transplant.



**DOUG PEARSON**  
A Fort Saskatchewan man who received a lung transplant four years ago.



**BHAVINI RUPARELL**  
She received a kidney transplant 27 years ago.



**MICHELLE REYNES** A living kidney donor who gave one of her kidneys to her husband.  
**DARREN REYNES** Received one of Michelle's kidneys and later received a pancreas from a deceased donor.



**BRIAN STEWART**  
Calgary father who received a kidney from one of his adopted daughters.



**JAMES VOGEL** Father from Drumheller who received a kidney from an anonymous living donor.



**TANYA SUMKA**  
An Edmonton mother of two who needs a heart transplant.



**TONY TIMMONS** Donated a kidney to Ryan McLennan.  
**RYAN MCLENNAN** Received a kidney from Tony Timmons. The two are now good friends.



**HARRY ZIRK**  
He said he knew without a doubt he wanted to donate whatever he could after he died.



**HEATHER ZIRK** An organ donation advocate who ensured her husband's tissue was donated after his death.



# MP to take a second swing at registry bill

Legislation would aim to include organ donor question on tax forms

SHAWN LOGAN

It's a crusade that began with his beloved wife's dying regret.

Calgary MP Len Webber has become a dogged advocate for increasing Canada's rate of organ and tissue donation, a fire that was kindled after his wife died of breast cancer in 2010.

"When she did pass away, she said the one regret she had was that she wasn't able to donate her organs," said Webber, who in October was elected to his second term in the House of Commons after serving for a decade as a Calgary MLA. "From there it just evolved. You start getting involved and the more you do that, the more you get motivated to do what you can."

Three years after her death, Webber's private member's bill, the Human Tissue and Organ Donation Amendment Act, was passed by the Alberta legislature, establishing a single agency to co-ordinate organ and tissue donations while also establishing a provincial organ donor registry. It further required agents at provincial registry offices to ask for people's consent to become an organ or tissue donor.

Soon after he was elected to represent the federal riding of Calgary Confederation, Webber started working on a plan to bring the conversation of organ and tissue donation to every Canadian household. He turned to taxes as a new lever to increase the nation's donor corps.

Last November, Webber received unanimous consent on Bill C-316, a private member's bill that will add a question on tax forms about whether people will consent to becoming organ and tissue donors. Those who sign up will then be added to the rolls of provincially

run organ donor registries.

"This is not a political issue, it is a human issue," he said in September 2018 in the House of Commons. "Any one of us could be in need of donor organs or tissues at any time. Just asking this simple question could increase the number of donors."

Despite consistent polling that finds about nine in 10 Canadians support the idea of donating their organs, only about 20 per cent nationwide have their names on donor registries.

Webber dedicated the bill to his friend Robert Sallows of Red Deer who received a double lung transplant when he was just 17, and had become an ardent supporter and counsellor to the Calgary MP as he crafted the proposed legislation, even through deteriorating health.

"He helped me lobby that bill even through his difficult time," said Webber, noting Sallows also helped him pass the bill that created Alberta's organ donor registry.

Sallows died just a week before the federal legislation passed second reading unanimously in a rare show of support across party lines.

It went on to the Canadian Senate but died on the order paper when the federal election was called in September, meaning Webber will now have to start the process anew.

Despite his disappointment, Webber expects the bill will now face a smoother ride among his parliamentary colleagues, though he admits the uncertainty of how it might be affected by a minority government is troubling.

"I do worry about minority governments because not a lot happens," he said. However, "a bill like this shouldn't be political. It's something all parties agree with so damn it, let's get it done."



Calgary MP Len Webber is seen here in 2013 with double-lung transplant recipient and organ donation advocate Helene Campbell. Webber is working to pass a bill to include an organ donation question on tax forms. *AMBER BRACKEN/FILES*



Darren Reynes, here with his wife Michelle, daughters Kaeden, 11, and Nevaeh, 13, and dogs Buddy and Nalla, has received both a kidney transplant and a pancreas transplant. *DAVID BLOOM*

## DARREN REYNES Patience an important part of the process

MOIRA WYTON

Darren Reynes didn't know that he was meeting someone who would be his partner for life — and much more — when he ran into an old high school classmate at an Edmonton bar during his university years.

He and Michelle, now his wife, had attended East Glen High School together, but hadn't spoken to each other much in those teenage years.

As adults, however, they hit it off and years later during their marriage they discovered that in addition to being a perfect pair they were also a perfect match.

Over the years, it became apparent Darren — who had been diagnosed with Type 1 diabetes as a child — desperately needed a kidney transplant. They eventually found out that Michelle's blood work revealed she could be his living donor.

"It gives me goose bumps because that's literally one-in-a-million kind of chances," said Darren, 48.

Darren had initially planned to receive a kidney from his older brother, but his brother died in a car accident in the midst of final testing in early 2002 before a match could occur.

So, Darren continued with dialysis, hoping there would be a

*If I had to redo it all over again, I would (take it) step by step, moment to moment to get to where I am today.*

deceased donor in the future who would be a match for him.

His health, however, worsened. After three years in total on dialysis, Darren told his wife that he was ready to stop fighting. He had experienced nearly every complication of the treatment possible, and didn't think life was worth living as he awaited a transplant he felt would never come.

"I didn't have a life," said Darren, noting that grieving his brother compounded his medical struggles. "It felt like I was spiralling down a rabbit hole."

But his wife wouldn't give up on him, and she encouraged him to swim each day to feel free and unencumbered and to explore more

options for finding a donor.

"We followed any glimmer of hope," said Darren, and that included looking for a living donor.

The two found one when Michelle's testing came back as a match in late 2003.

The transplant in January 2004 went smoothly, and Darren has had no rejections in almost 16 years.

However, the underlying cause of Darren's kidney failure — a secondary complication of diabetes — would also require a pancreas transplant.

The call for that transplant came just days after the birth of their second daughter in 2008.

After multiple infections and more than a year of recovery, Darren came through the other side of transplant surgery for a second time.

"If I had to redo it all over again, I would (take it) step by step, moment by moment, to get to where I am today," said Reynes.

Now, he and his wife speak at pre-habilitation sessions and support other families considering living donation whenever they can.

Darren said patience is often the hardest part of the process, but also the most rewarding.

"Hope becomes invisible," he said. "But if you can find it, and you have that support, those are probably the two most important things you can have."

## DREW BRABBINS Living for today while hoping for tomorrow

MOIRA WYTON

Pre-lung transplant patient Drew Brabbins ensures he remains on the move.

For most people, getting to the gym five times a week is an ambitious goal. But for Drew Brabbins, it's non-negotiable.

The 58-year-old spends every weekday morning working out alongside other people with lung conditions at the GF MacDonald Centre for Lung Health in Edmonton.

"This is a place where I can go to work out, get to know people, talk to people who have maybe not the same problems that I have, but are dealing with the same issues," said Brabbins from his Sherwood Park home. "Everyone is on oxygen, so you go there and that's normal."

Brabbins was diagnosed with asbestosis from an unknown exposure at age 38. He developed emphysema and chronic obstructive pulmonary disorder as a result.

For more than two years, he has been on the lung transplant waiting list.

Once an active individual who played all kinds of sports, Brabbins still ensures he works on his fitness. He says it has not only helped his mental health, but is also increasing his chances of a transplant being successful when lungs become available.

"It's so important," Brabbins said. "Just getting off the couch in the morning helps."

Using oxygen 24 hours per day, Brabbins' time outdoors is limited in cold, smoky or rainy weather. He said he misses spending time outside with his grandchildren, as he "watches the world from the window."

Now, with five other patients he met in a pre-habilitation course (they call themselves the Group of Six), Brabbins speaks to other

patients awaiting transplants and highlights the benefits he's achieved by focusing on fitness.

Brabbins and his wife Bonnie also hope that by educating children about the importance of organ donation will lead to an increase in donor numbers as the students grow into adults. They hope it also leads to a decrease in the stigma that sometimes surrounds organ donation. "Kids are the ones that are more receptive to hearing this stuff than the 25-year-olds who think they are bulletproof and don't want to hear about their mortality," he said.

Brabbins said he thinks the mental toll waiting for "Christmas" (the word he uses to describe the day when he will get that call to tell him a donor match has been found) would be even more difficult to manage without focusing on what he can do for himself and others in similar situations.

"I'm not waiting for tomorrow, but I'm hoping for tomorrow," he said. "You just need to get through each day and eventually Christmas will come."



Drew Brabbins, here with his wife Bonnie, used regular exercise to stay healthy while waiting for a lung transplant. Since speaking with Postmedia for this story, Brabbins has received a transplant. *IAN KUCERAK*

### EDITOR'S NOTE

Drew Brabbins received a lung transplant shortly after speaking to Postmedia and is doing well.



EDITORIAL

OUR VIEWS

SHARE YOUR GIFT OF LIFE

When it comes to the topic of organ donations, it seems Canadians are better at talking the talk than walking the walk.

Polls show that almost nine in 10 of us support the idea of organ donation, but only two in 10 actually sign donor cards. It raises an important question: Why do so many people support the idea in theory, but not in practice?

It's no longer a question of convenience; it's easy to become an organ donor. We can sign up online. Or, we can just say "Yes," when the now-mandatory query — of becoming an organ donor — is raised as we renew our driver's licences.

Rather, the gap between intention and action may be better explained by a lack of awareness and lack of communication. While many people may want to donate organs, they, unfortunately, don't tell their families.

The importance of expressing this wish can't be overstated, say Bernadine and Toby Boulet, whose son Logan lost his life in the Humboldt Broncos bus crash. Because Logan had previously stated he wanted to donate his organs, his parents knew what to do. The decision not only saved the lives of those who received Logan's organs but also sparked a significant increase in the number of people signing up to be donors.

Logan's actions underscored the need for organs in Canada. As also highlighted in the Postmedia series Gifts of Life published throughout November, the need can strike anyone at any time, be they young or old, poor or rich.

The good news is that Alberta achieves remarkable success with its transplant programs. Edmonton's University of Alberta Hospital offers the most comprehensive organ and tissue transplant program in Canada, ranking sixth in the world for transplanting excellence. Last year alone, doctors at the U of A performed more than 350 organ transplants, including heart, lung, islet, kidney, liver, pancreas, eye, tissue and small intestine transplants.

The not-so-good news, however, is that for every patient who receives a life-saving organ, there is another patient waiting. Last year saw 2,800 organ transplants performed nationwide, but nearly 4,500 Canadians were left on the wait list, including 654 from Alberta. Another 643 across Canada, including 46 in Alberta, died or were removed from those lists.

Those who have agreed to donate a loved one's organs after death and those who have generously become living donors wonder why more people don't do the same. Who wouldn't want to save the life of a fellow human being?

Theoretically, we all know the answer. Now it's time to put theory into practice.

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"During the holidays, we like to refer to organ donation as 'regifting.'"

More donors needed for stem-cell registry

Agency keen to widen racial diversity, of offerings, says *Dr. Heidi Elmoazzen*.

Two years ago in Calgary, Revée Agyepong received the gift of stem cells. As a toddler, more than two decades ago, she was diagnosed with sickle-cell anemia — one of the 80 diseases and disorders that can be treated today with blood-forming stem cells. In 2018, she was fortunate to match with her sibling — fortunate because only one in four patients match with a family member.

Every year, hundreds of Canadians require a life-saving stem cell transplant to treat blood cancers and disorders such as leukemia, lymphoma, aplastic anemia, and inherited immune and metabolic disorders. Most rely on the generosity of an unrelated donor.

The first step in saving a life can be as easy as joining Canadian Blood Services Stem Cell Registry, the public registry responsible

for recruiting and finding healthy, committed volunteer donors. But that's just the beginning for those who want to make a difference.

Who's the ideal stem cell donor? We're especially interested in male donors between the ages of 17 and 35, who tend to result in better outcomes for patients. Also, we're looking for donors from all kinds of ancestral backgrounds.

Everyone has specific inherited genetic markers, and patients are more likely to find a successful match from a donor with similar ancestry. Patients of diverse ethnic or mixed-race backgrounds often face a much steeper hill when searching for a matching donor, and we want to change that. For example, patients of Caucasian or European descent have a 75 per cent chance of finding an optimal donor, while patients

of black African descent have only a 16 per cent chance. That is why building a stem cell registry that reflects the unique diversity we see here in Canada is critical.

To significantly increase the odds of finding a matching stem cell donor for all patients, Canada's registry belongs to an international network of registries to match potential donors and recipients around the world. With roughly 455,000 Canadian registrants and access to more than 36 million potential stem cell donors through this network, the odds of finding a match are much, much higher.

Even though Canadian Blood Services tells new registrants that registering requires a long-term commitment, sometimes for years, about half of those contacted from the registry to launch the actual donation process decline to proceed with the donation. This is potentially devastating for the patient.

This past year alone, Canadian Blood Services Stem

Cell Registry conducted more than a thousand new unrelated donor searches for Canadian patients. More than 400 Canadian patients received a stem cell transplant from Canadian and international donors, and 116 Canadians donated to patients in Canada and around the world. Everyone who joins the registry is providing hope to patients waiting for a stem cell transplant.

The quickest way to register is online at blood.ca. We also encourage you to learn more about joining Canada's Lifeline by donating stem cells, umbilical cord blood, blood, plasma and organs and tissues.

You can also help Canadian patients by volunteering your time, giving a one-time or recurring financial donation, organizing group donations in collaboration with another organization or community, or even sponsoring a donation event.

*Dr. Heidi Elmoazzen is stem cell director for Canadian Blood Services.*

Presumed consent bill unlikely to shorten transplant wait lists

Public must first be better informed on benefits of donation, *Susan Muncner* says.

Bill 205, Human Tissue and Organ Donation (Presumed Consent) Amendment Act has cleared a couple of hurdles and stands a good chance of moving forward in the Alberta legislature. What does it mean for organ donations?

"Presumed consent" assumes that anyone who did not indicate their explicit refusal to become an organ and tissue donor should be considered for donation.

While those who support organ and tissue donation are anticipating celebrating an unprecedented victory towards raising low rates of donation in Alberta, those on the other side of the spectrum may feel their rights to autonomy slipping through their fingers. Neither of these responses is warranted.

Presumed consent, or "opt-out," donation policy has been

established in many jurisdictions around the world, such as Spain, Belgium, and Austria. While it may seem like an obvious way to increase donations, studies have shown that the effectiveness is minimal at best. Spain, the world's organ and tissue donation gold-standard, has operated under presumed consent since 1979. But its jump to No. 1 did not happen until a decade later when it organized a national transplant organization and funded a robust donation program.

In reality, presumed consent as per Alberta's Bill 205 will not change much. Currently, regardless of whether someone had signed their consent to donate through the Albertan Organ and Tissue Donation Registry (ultimategiftalberta.ca), families and next of kin are still consulted regarding their and the potential

donor's presumed wishes. Under the new legislation, although all patients are considered potential donors until otherwise deemed unfit for donation (unless they previously signed their refusal to donate), families will still be consulted and have the final say.

In this case, everyone anxious about the possibility that their loved one is whisked away against their wishes, all because they forgot or did not have the time to sign their refusal before they died, can rest assured.

However, there are two key measures in Bill 205 that may help increase donation rates.

First, there is a section instituting mandatory referral to donation organizations. Donation organizations are crucial: they are teams of nurses and physicians who co-ordinate the suitability of donors and recipients, and organize the transplant of organs efficiently. Under current law, physicians are required to document and consider potential donors for referral to

organ donation organizations. Potential donors are lost each year because referrals were not completed, for myriad reasons. In Bill 205, these referrals would be mandatory and this may help improve the number of donors that donation organizations can assess for transplantation.

Second, there is the mandatory quarterly reporting to the minister of health on the mandatory referrals statistics and missed referrals. While this is an excellent start to accountability, in the future there needs to be continuous real-time auditing and feedback to practitioners of missed potential donors, with the provision of education to them to support best practices.

Although presumed consent may seem like a clear solution to the problem of low donation rates, one of the most important pieces of the puzzle is to increase public support for donation. Currently, although over 90 per cent of Albertans claim to support organ and tissue donation,

50 per cent of families consulted in the time of a crisis, will refuse donation. The public needs to be better informed. One donor can save up to eight lives through organ donation and can improve the lives of up to 75 through tissue donation. Hundreds of Canadians die each year waiting for a transplant, and the lucky ones who do receive the "gift of life" continue to live full, happy lives with their families.

Every year in Alberta, the need for organs and tissues grows. Although Bill 205 does contain a potentially influential amendment for mandatory referral and reporting, no real change will occur only through presumed consent. Public awareness of the importance of organ and tissue donation needs to be in place, and funding for organ donation organizations and support of other organ and tissue donation best practices need to keep pace as well.

*Susan Muncner is a medical student at the University of Alberta.*



# Gifts of Life

Samples of social media posts from Nov. 2019 project

**Calgary Herald** ✓ @calgaryherald · Nov 1, 2019

'It's either that or you die': Desperate billboard campaign leads to donated kidney — and friend for life [bit.ly/338oX1G](https://bit.ly/338oX1G) #giftsoflife #organdonation



**Calgary Herald** ✓ @calgaryherald · Nov 29, 2019

Presumed consent could shorten transplant waiting lists. Will Alberta follow Nova Scotia's lead on legislation? #yyc #OrganDonation #OrganTransplant #abpoli #GiftsOfLife [bit.ly/33tXkj3](https://bit.ly/33tXkj3)





This post reached more than 35,000 people on Facebook and was shared 240 times.



number of health issues have led to kidney disease, a 50-pound weight loss, a long list of prescribed drugs and the need for regular dialysis. It's a fate he says he wouldn't wish on his worst enemy.

Charles needs a new kidney. While he was hoping one might become available within a year, he's been told it will likely be closer to five or seven years until it's his turn to receive the organ.

"I've never asked anyone for help for anything in my life," he says. "But it scared me to death thinking this is what my life is going to be now. I realized it was a fact that nobody was going to help me if I don't ask."

Charles has launched a social media campaign to publicize his need for a kidney and to provide a candid glimpse into the life of a person with renal failure.

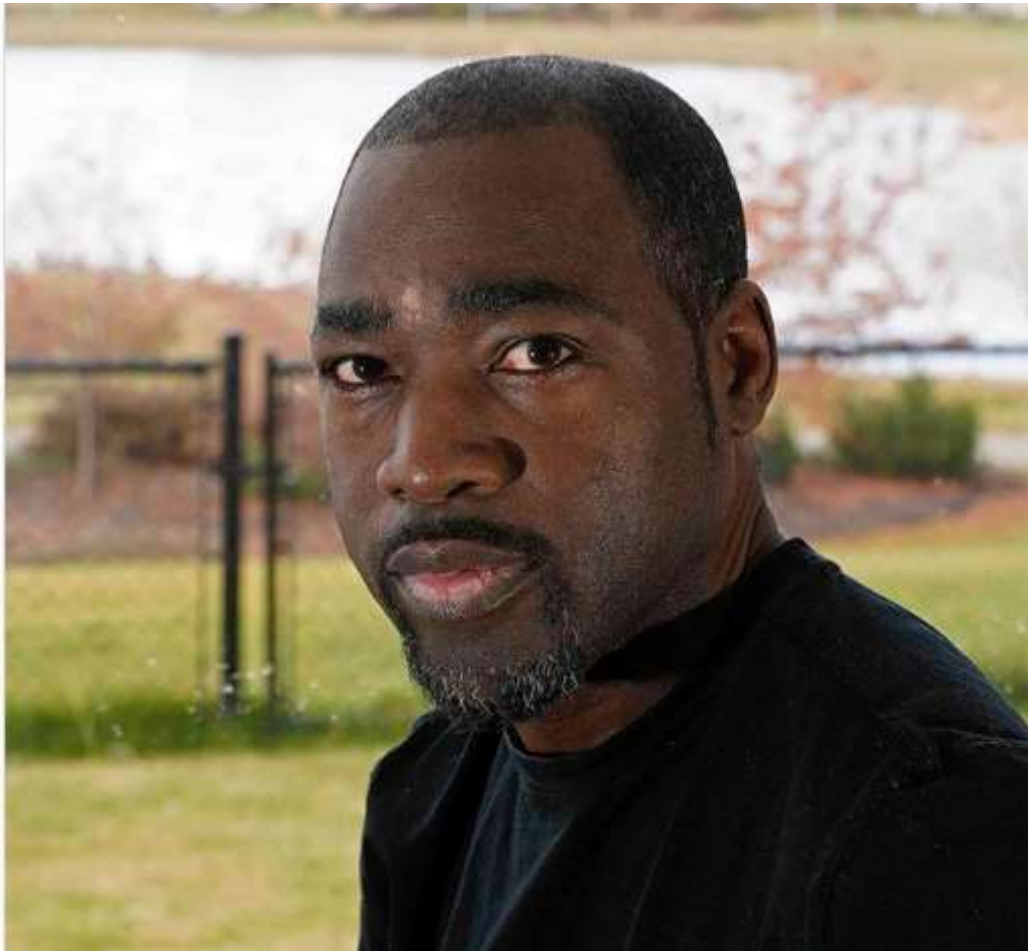
For more on organ donation in Alberta, read our new series Gifts of Life here:  
<https://calgaryherald.com/tag/gifts-of-life>

If you or someone you know has a story about organ donation to share, please email us at [submit@calgaryherald.com](mailto:submit@calgaryherald.com)





A similar post on Instagram reached an additional 8,900 people, also garnering 193 likes.



**melshortall87** Thank you for sharing (t)his story. I remember my dialysis journey, boy was the road was tough. It's something one cannot truly appreciate until you've been hooked up to a machine for hours on end. I pray he gets his kidney soon. I am one of the fortunate ones, I'm almost 2.5 years post transplant. Hope was what got me through it  
[#shareyourspace](#) [#kidneytransplant](#)  
[#kidneyfoundationofcanada](#)  
[#chronickidneydisease](#)

11w 2 likes Reply



**tia81123** 👍❤️

10w Reply



193 likes

NOVEMBER 4, 2019



This Facebook post reached 11,000 and was shared 61 times; it even attracted a potential kidney donor! (See Andrew Archer comment below)



HERALD • November 14, 2019 • 🌐

Edward Schmidt, 57, has been diagnosed with a “virtually incurable” disease and his last hope is an organ donor. Schmidt is fighting end-stage kidney disease and has been undergoing hemodialysis to treat his kidney failure. “What organ donation means to me is another chance at life,” he said. His kidney function has significantly declined in the past year after facing a range of diagnoses since h...  
[See More](#)

👍❤️ 31

4 Comments 61 Shares

👍 Like    💬 Comment    ➦ Share    👤 ▾

Most Relevant ▾



**Cheri Lynn Spence** My 17 yr old niece is facing renal failure too my heart goes out to anyone having to endure the complications 🙏

Like · Reply · 9w



**Mary Margaret** Very sorry, Oi ts heartbreaking 🙏🙏

Like · Reply · 9w



**Andrew Archer** Hi Ed, if I can call you Ed.. more info on blood type and such would be helpful to anyone encouraged to help. I myself am A+ and would be willing to donate



This Instagram post was seen by more than 8,000 people and liked more than 200 times.





## Some of the tweets related to the project

**Calgary Herald** ✓ @calgaryherald · Nov 1, 2019

Poll after poll has found that nine in 10 Canadians support the idea of donating organs and tissue to those in need, but only around two of those 10 have made the conscious effort to sign donor cards.

#LoganBouletEffect #GiftsofLife #organdonation #yyc [bit.ly/2qchh](https://bit.ly/2qchh)



**Calgary Herald** ✓ @calgaryherald · Nov 1, 2019

Organ donations: What you can do to help save a life [bit.ly/2oCu1](https://bit.ly/2oCu1)  
#yyc #Alberta #organdonation #giftsoflife





# Some of the additional tweets related to the project

**Calgary Sun** ✓ @calgarysun · Nov 29, 2019

MP Len Webber continues fight to add donor consent to tax form  
[#OrganTransplant](#) [#OrganDonation](#) [#cdnpoli](#) [#GiftsOfLife](#) [bit.ly/3...](#)



**Calgary Herald** ✓ @calgaryherald · Nov 1, 2019

The bold white and green billboard was hard to miss for visitors descending into the Drumheller valley over the last few months.

"Someone we love needs a kidney donor. Type A+." [bit.ly/339JsuP](#)  
[#GiftsofLife](#) [#Organdonation](#)






# Some of the additional social media posts related to the project



[View Insights](#)




 Liked by **stephaniebaby** and **others**  
**calgaryherald** Kendra Lee-Rankin was just five days



[View Insights](#)



 Liked by **stephaniebaby** and **others**  
**calgaryherald** Kendra Lee-Rankin was just five days



## Some of the additional social media posts related to the project



Liked by **stephaniebaby** and others

**calgaryherald** Kendra Lee-Rankin was just five days



**calgaryherald** Kendra Lee-Rankin was just five days old when she had her first open heart surgery. A birth defect meant her heart wasn't functioning properly. The surgery saved her life, but it was the first of many. By the time she was 22, she'd had more than 14 surgeries. "I didn't really know any different," she says of her childhood, during which she loved playing with friends but often couldn't keep pace with pals and siblings. "It would be nice to know what normal is," she adds. Lee-Rankin hopes she and her husband will someday be able to adopt children, but the focus right now is her health, waiting for a heart transplant and spreading the word that as many people as possible should sign up to become organ donors. "Tomorrow's not guaranteed for anyone," she said. "I'd rather go knowing I had done everything I can." [#giftsoflife](#) [#organdonation](#) [#alberta](#)





## Some of the additional social media posts related to the project



[View Insights](#)



Liked by **stephaniebabych** and others

**calgaryherald** Born with a bladder blockage that caused one of his kidneys to fail as an infant, Sean Delaney received a donated kidney from his brother in a pre-emptive transplant when he was 28 years old in 1998. His quality of life was greatly improved after the transplant and until last year, things remained relatively stable. But a series of health

problems have led to the need for a second kidney transplant and Delaney has started a social media campaign to find a donor. So far, he notes that 25 potential donors — whom he did not previously know — have reached out to him through his posts on social media, where he is documenting his journey. "That's 25 people who are otherwise healthy, who don't need to have surgery, who are willing to go under a knife for nothing but saving my life," said Delaney. "That's pretty humbling." Delaney's job also reflects his involvement in the world of transplantation. He is the associate director of organ listing and allocation at Canadian Blood Services, meaning he works to streamline organ donation across the country and promote the importance of this precious gift. Talking about being a donor is one of the most important conversations people can have with their families, he says. It's essential. To read more visit our series Gifts of Life at [calgaryherald.com](http://calgaryherald.com) [#yyc](#) [#giftsoflife](#) [#organdonation](#)

[View 1 comment](#)

November 6, 2019



# Some of the additional social media posts related to the project



calgaryherald



[View Insights](#)



Liked by **dbaisley** and others

**calgaryherald** For Tanya Sumka, it's thoughts of her two children — Victor and Ivonna — that get her through the toughest days. For 12 years, she's been living with viral cardiomyopathy — an infection that causes acute inflammation and weakness of the heart muscle. Sumka's condition worsened three years ago, meaning she now is connected to a left-

ventricular assist device 24 hours a day and awaiting a heart transplant. The device limits her mobility, but she still tries to stay optimistic with hopes a heart that is a match for her will arrive. Sumka says that a heart represents "a second chance at still having the life that I know; that I potentially could have another 20 years to see my children grow up," she says. "That's my dream." She adds it's also difficult to know that if that heart arrives, it will be because another family has experienced a horrible tragedy. Because of that, she knows that when she gets a heart she has a responsibility to make the most of it. The transplant represents the donor's legacy. "It is a miracle," she says. Visit [calgaryherald.com](http://calgaryherald.com) to read more from our series [#GiftsofLife](#). [#organdonation](#) [#alberta](#)

November 5, 2019



# Some of the additional social media posts related to the project

Calgary Herald November 5, 2019 · 🌐

For Toby and Bernadine Boulet of Lethbridge, whose 21-year-old son Logan was killed in last year's devastating Humboldt Broncos bus crash, they were fortunate enough to have known his wishes before his untimely death.

"We really advocate having a conversation and to talk to your family so that people know what your wishes are," said Bernadine.

Read the story now: <https://calgaryherald.com/.../logan-boulet-effect-is-a-boost-...>



Calgary Herald November 23, 2019 · 🌐

Tanner Fitzpatrick and Mark Klassen live more than 6,000 kilometres apart, on opposite sides of the country, but both proudly sport tattoos that honour the sacrifice of a young Calgary woman who decided as a teenager to become an organ donor.



CALGARYHERALD.COM

**'We know our daughter has had an impact': Young hero saved lives by donating organs**