



**kidney**  
FOUNDATION

2020 IMPACT REPORT

# COMING TOGETHER IN A TIME OF NEED



SPECIAL SUPPLEMENT INCLUDED

IMPACTS & OUTCOMES  
OF KIDNEY RESEARCH  
IN CANADA

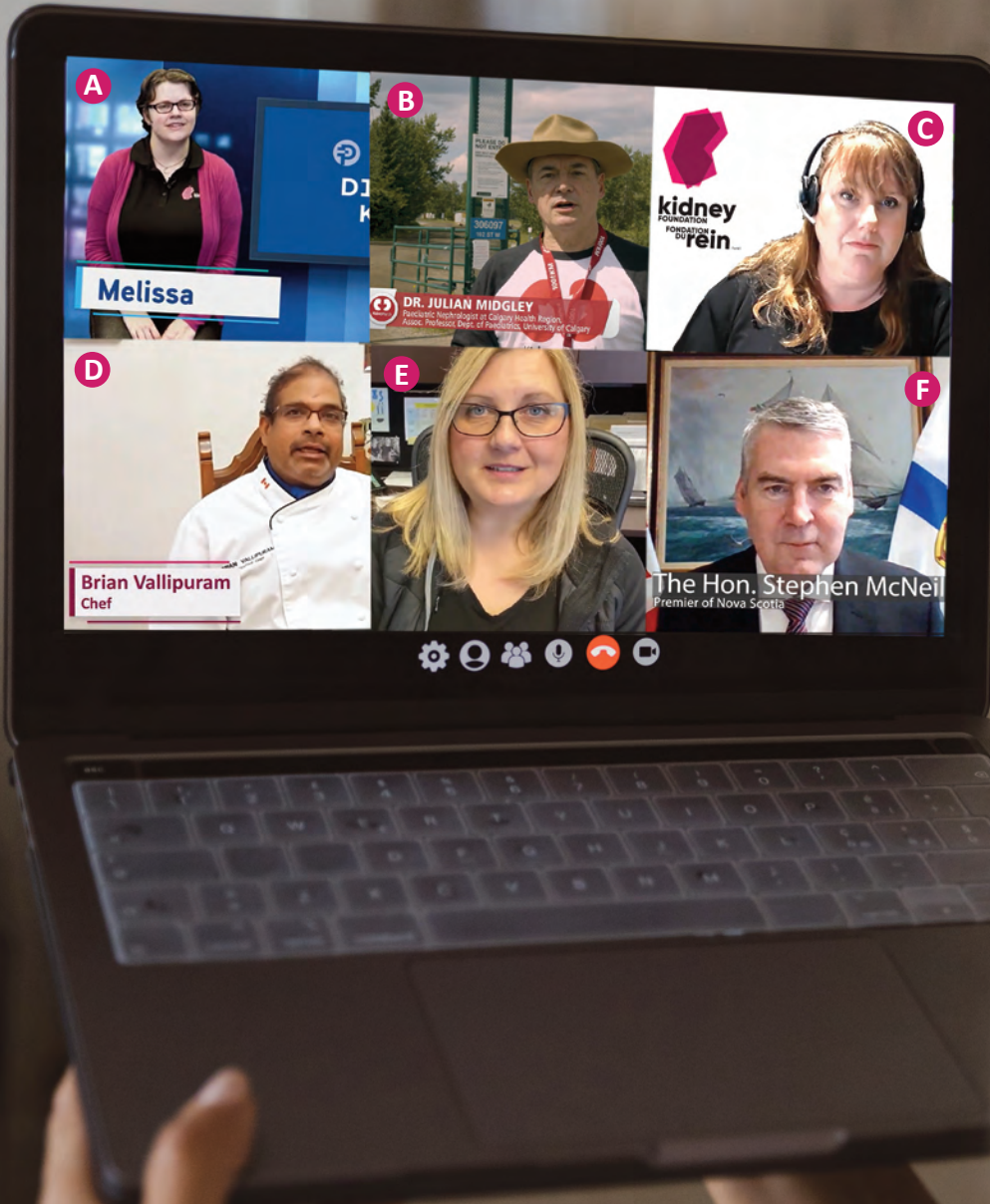
## Our Vision

The Kidney Foundation of Canada is committed to achieving excellent kidney health, optimal quality of life, and a cure for kidney disease.

## Our Mission

The Kidney Foundation of Canada is the national volunteer organization committed to eliminating the burden of kidney disease through:

- Funding and stimulating innovative research for better treatments and a cure;
- Providing education and support to prevent kidney disease in those at risk and empower those with kidney disease to optimize their health status;
- Advocating for improved access to high quality healthcare;
- Increasing public awareness and commitment to advancing kidney health and organ donation.



## STAYING CONNECTED DESPITE BEING APART

- A** Melissa Lackie hosts an informational PLUGGED-IN episode broadcast on Shaw Cable
- B** Dr. Julian Midgley explains how Kidney March will take place virtually to ensure safety is a top priority
- C** Lydia Lauder, National Director of Programs and Public Policy, introduces an expert speaker during an online webinar
- D** Chef Brian Vallipuram offers kidney-friendly nutritional advice

- E** Jill Goth, a member of The Kidney Foundation's Programs and Public Policy team offers a reassuring message that services will not be interrupted
- F** The Honourable Stephen McNeil, Premier, Nova Scotia, recipient of The Kidney Foundation of Canada Organ Donation & Transplantation Award, talks about the importance of organ donation

**Cover photo:** Scott, Chris, Jacqueline and Barb participate in the 2020 Kidney Walk while following all local public health guidelines in place at the time

# MESSAGE FROM THE PRESIDENT AND NATIONAL EXECUTIVE DIRECTOR

COVID-19 has weighed heavily on all of us this past year, but especially on those who are living with or impacted by kidney disease, whether they're on dialysis, waiting for a transplant, or are transplant recipients. It's a scary time for anyone who has a suppressed immune system or has to make regular trips to the hospital for dialysis.

Thanks to the ongoing generosity of our donors and supporters, The Kidney Foundation was able to pivot quickly and provide the information and support that our kidney community needed to stay safe and connected. We quickly transitioned our programs and services to a virtual environment:

- We shared timely COVID-19 information and guidelines on our website
- We enhanced our vital peer support program to provide increased access to virtual connections and support
- We increased short-term financial assistance to those impacted by the pandemic, at a time when people needed it more than ever.

COVID-19 also had a significant impact on our research community, as labs were closed then needed to start things back up several months later. The Kidney Foundation paused its research grant payments briefly during the first wave, but is firmly committed to honouring its research commitments in full and to maintaining the highest priority on research. In addition to funding 103 research grants, we are key partners in national research initiatives such as Can-SOLVE CKD, and have partnered

with the Canadian Institutes of Health Research to provide \$2 million to fund much-needed research into diabetic kidney disease.

We could never have weathered this COVID storm without the amazing support and commitment of our donors, volunteers, and staff. The charitable sector was hit hard by COVID-19, as traditional fundraising events and other activities were cancelled, and we are grateful to all of you for your unwavering and generous support at a time when our community needed it most.

It is hard to remember what things were like before COVID-19, but way back at the beginning of 2020 The Kidney Foundation launched its new brand, one that is bold, modern, and disruptive in a positive way to spark change – in short, like us. With this new look, and with your support, we remain as committed as ever to our vision of a future without kidney disease.



**SYLVIE CHARBONNEAU**  
*National President*



**ELIZABETH MYLES**  
*National Executive Director*

# SAFEGUARDING PEOPLE AFFECTED BY KIDNEY DISEASE

## AN ENTIRE COMMUNITY RALLIES TOGETHER IN A TIME OF NEED

The official declaration of a pandemic on March 11, 2020 immediately affected everyone in some way. Canadians rapidly changed habits and routines to safeguard their health and that of their loved ones. The pandemic forced us to work differently and socialize differently, and to exercise unprecedented precaution. It has been a time of great stress, and of great loss.

Due to chronic health conditions or immunosuppression, people requiring dialysis treatments and those who received a kidney transplant were at greater risk should they become infected with the COVID-19 virus. The community of professionals who work in the field of renal care and organ transplantation immediately began to safeguard the health of patients, as it quickly became apparent its effects were likely to be more severe on that population.

The Kidney Foundation also took action to ensure that the programs and services vital to those impacted by kidney disease would not be interrupted and to support dissemination of important information to the kidney community.

## DIALYSIS PATIENTS

Study of the total impact of the pandemic on people receiving dialysis treatments is ongoing. Since health care is a provincial or territorial portfolio, gathering data for a national perspective within such a short time frame can be challenging and data collection methodologies can vary from one jurisdiction to the next. Nevertheless, necessary steps were taken in the early days of the pandemic to mitigate the issue.



DR. DEBORAH ZIMMERMAN

Dr. Deborah Zimmerman, director for clinical research at the Kidney Research Centre and past president for the Canadian Society of Nephrology explains: “At the beginning of all of this, we had the good fortune of working with the Senior Renal Leaders’ Forum to come up with guiding principles to help with the management of people with kidney disease.”

Most of the available data is about patients receiving in-centre hemodialysis, as this group was affected far more significantly than those receiving home hemodialysis or peritoneal dialysis. According to a

paper published in the Canadian Medical Association Journal, the proportion of in-centre hemodialysis patients in Ontario who have tested positive for COVID-19 is six times greater than that of home hemodialysis patients and 2.5 times greater than that of peritoneal dialysis patients.

Since March 2020, a great deal of variance in COVID-19 infection rates has been observed within the population at large from one province to another. Dr. Zimmerman suggests that this may be due to differences in provincial responses, population density, or behavioural factors such as travel. Similar provincial variations exist in the prevalence of the virus for in-centre dialysis patients.

For example, Dr. Zimmerman explains that, as of January 2021, the general population prevalence of COVID-19 in British Columbia (based on 2016 census data) was 1.23%. For dialysis patients in that province, it was 1.5%. By comparison, 1.73% of Ontario’s general population reported testing positive for COVID-19, whereas the rate within the dialysis population was 4%.

In Quebec, the province hardest hit by the pandemic in terms of COVID-19 cases per capita, the numbers tell a slightly different story.

At the beginning of the pandemic, Dr. Rita Suri, Associate Professor and Director of the Division of Nephrology at McGill University, began a study with her colleagues to examine the impact of COVID-19 on dialysis patients in Quebec. The project, funded by



DR. RITA SURI

the Canadian Institutes of Health Research, received participation from all but one dialysis center in Quebec. The cohort represents roughly 400 patients.

Preliminary findings of the study indicate that one in 10 hemodialysis patients in Quebec has been infected with COVID-19 over the last year. Approximately half of them were hospitalized and more than 20% have died.

Although in-center dialysis patients in Quebec had a high rate of infection, Dr. Suri believes that most of it came from the community. “So, if you lived in a community where there was a high prevalence, such as in the greater Montreal area, then yes, we had cases in the units. But none of them came from within the units.” Most dialysis units put protective measures in place fairly quickly and no outbreaks occurred in those units during the first wave. “Even the units that were crowded came up with very creative solutions to try and keep patients safe,” reports Dr. Suri.

## ORGAN DONATION AND TRANSPLANTATION

The organ donation and transplantation community pooled its resources very quickly through Canadian Blood Services (CBS). “CBS got all the provinces and their organ donor organizations and transplant programs contributing data as to what was going on in their jurisdiction and how they were approaching best practice towards trying to keep programs open,” notes Dr. Peter Nickerson, Medical Director of Transplant Manitoba and the Medical Advisor, Organ Donation and Transplantation Division, Canadian Blood Services.

The Canadian transplant community also had regular calls with their counterparts in other parts of the world, many of which were experiencing very similar circumstances, and they received insights into best practices to help deal with the situation.

According to data gathered by CBS, in 2020 there had been a marked reduction in kidney transplantation activity, both in relation to living donor kidney transplants and deceased donor kidney transplants. There were 20% fewer kidney transplants in 2020 than in 2019. However, there were some regional differences. For example, in Manitoba, there were more kidney transplants in 2020 than in 2019 thanks in part to an extraordinary number of transplants that took place in January and February.

CBS data shows that, in the first few weeks of 2020, Canada was on track to maintain similar levels of deceased organ donations as in previous years. As the first wave of the virus began, donations immediately dropped significantly. Donation rates improved in the summer as the wave subsided, but never returned to previous years’ levels. Although the second wave was more severe, it did not bring about as dramatic a decrease as the first. The result in 2020 was that deceased kidney donation activity was down 12% compared to the previous year.

The living organ donation rate also went down in early March. It was a period of great uncertainty and many unknowns for the medical community. Therefore, for the safety of patients, living donation programs were paused across the country to avoid bringing patients into a hospital environment where the virus might be present.

It was decided to defer living donor transplants until new pandemic-management logistics could be in place that ensured the health and safety of patients and donors. Here too, the summer months brought a renewal in activity as programs resumed.



DR. PETER NICKERSON

With the advent of the second wave, living donation rates slowed down once again; however, thanks to the safety policies and procedures introduced in hospitals, greater success was achieved in keeping the programs open. Data gathered by CBS shows that, by the end of 2020, the living organ donation rate was down 37% compared to 2019.

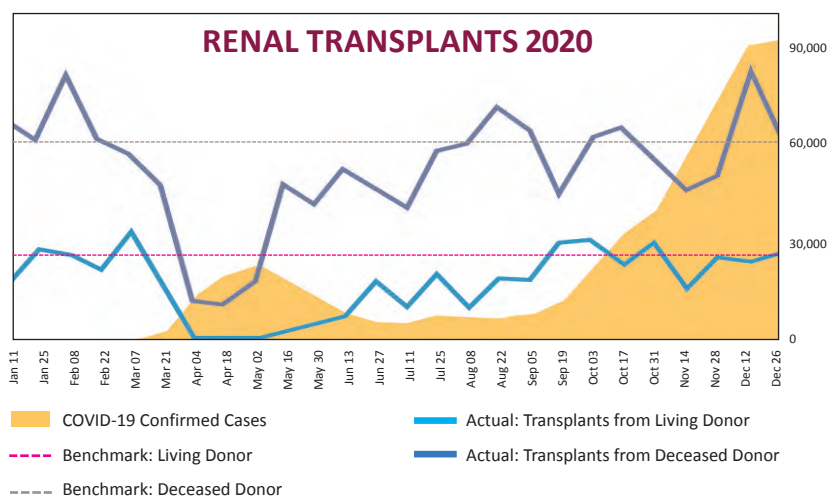
Dr. Nickerson, who also serves as co-chair of The Kidney Foundation’s Research Council, suggests that while transplant rates during the second wave did not decrease as significantly as they had in the first, the greatest challenge has been related to available resources within the hospital. When intensive care units are operating well beyond their capacity, it has an important impact on the rest of the hospital.

Dr. Nickerson notes that, with COVID, programs tended to become more conservative about which organ donations they would proceed with to increase the chances of a rapid recovery and get patients in and out of the hospital as quickly as possible. According to Dr. Nickerson, one of the side-effects of the pandemic was a decrease in organ donors because people were less active and stayed home. This resulted in fewer instances of events that normally lead to donation activity, such as heart attacks and traffic accidents.

Another unexpected trend brought about by the pandemic is that waitlists for organ transplants are going down. “The workup process requires multiple visits to the hospital to get access to diagnostic tools and other evaluations,” explains Dr. Nickerson. “Patients don’t want to come if they don’t have to. So, we’re seeing the number of people going on the waitlist has gone down because fewer patients are being worked up.” He suggests that there is another future backlog on the horizon – that of processing patients to prepare them for a future transplant.

↓ 20%

OVERALL, THERE WAS A 20% REDUCTION IN KIDNEY TRANSPLANT ACTIVITY



Data Source: Canadian Blood Services, National Organ Donation and Transplantation COVID-19 Impact Data, 2021

## STRESS AND EMOTIONAL WELL-BEING

Based on her own observations and conversations, Dr. Zimmerman expects the emotional and psychological repercussions of the pandemic on people living with kidney disease will be significant. For a while during the first wave, living donor kidney transplants stopped, and transplants from deceased donors slowed down. Dialysis patients were less likely to receive a transplant and were unable to be told when they might resume. “I imagine that had huge implications for their mental health, but I haven’t seen a publication where it has been measured,” she notes.

A qualitative survey of patients is also an important component of Dr. Suri’s study. “Patients have expressed worries about getting COVID from outside of the dialysis unit, in their day-to-day activities,” explains Dr. Suri. “But they are generally confident with respect to their dialysis units.”

Some respondents of Dr. Suri’s survey found it difficult due to transportation problems, such as drivers not coming for fear of getting infected. Others expressed sadness due to the absence of interaction with other patients or people outside their homes, and being more isolated.



NICOLAS FERNANDEZ

It is a sentiment that is echoed by Nicolas Fernandez, a transplant recipient and volunteer co-chair of The Kidney Foundation’s Research Council. “The biggest effect on me has been the isolation. I have to stay home because of my vulnerability.”

Nicolas has been dealing with having very limited face-to-face contact with others and fewer opportunities to go out. “The more time goes by, the more I ask myself what it was like before. I’m losing sight of what it was like to hug somebody.”

He has relied greatly on the internet to help combat the sense of isolation and loneliness. “I’ve kept up my friendships with a lot of people. We have suppers together via Zoom,” he explains. “It’s amazing how close we can feel even though we’re not together.”

## HOW THE KIDNEY FOUNDATION SUPPORTED PEOPLE LIVING WITH KIDNEY DISEASE

Support and services for people affected by kidney disease provided by The Kidney Foundation were uninterrupted in 2020 despite a marked increase in requests and staff working remotely with little notice. Short-term financial assistance requests were among those that experienced the greatest spike. In the early weeks of the pandemic, some parts of the country saw their requests grow five times greater than during the same period the previous year, while others reported receiving requests for items such as blood pressure monitors because access to these in pharmacies and supermarkets became limited.

Uncertainty can be a source of stress. In the spring of 2020, there was a great deal of information – and sometimes misinformation – coming from innumerable sources, including social media, traditional media, and government agencies. In order to provide up-to-date, reliable and pertinent information for Canadians affected by kidney disease, The Kidney Foundation dedicated an informational page on its website at [kidney.ca/covid-19](http://kidney.ca/covid-19). Data and information were updated regularly.

The website offered kidney patients and transplant recipients signs which could be downloaded, printed, and affixed to their front door explaining that residents at that address are immunocompromised and unable to welcome visitors.

As well, the Foundation offered information and support via several COVID-themed webinars featuring leading Canadian renal experts. Topics included COVID-19 and Dialysis Patients, COVID-19 and

Transplant Patients, COVID, Kidneys & Coping: Ask Your Social Worker, and COVID-19 and Your Renal Diet. Additional nutrition and grocery buying tips were provided via blog posts on the Kidney Community Kitchen website.

Peer-support activities were rapidly moved to an online environment to ensure people received the support and assistance they needed as safely as possible.



In the summer months, The Kidney Foundation initiated a survey to help assess the impact of the pandemic on people with kidney disease and their families. A vast majority of respondents reported experiencing feelings such as anxiety, depression, or exhaustion since the pandemic began.

In parts of Ontario where adapted public transportation was suspended, The Foundation intensified its advocacy efforts to underscore the urgency of providing reliable access, particularly for those who rely upon it to get to their dialysis appointments.

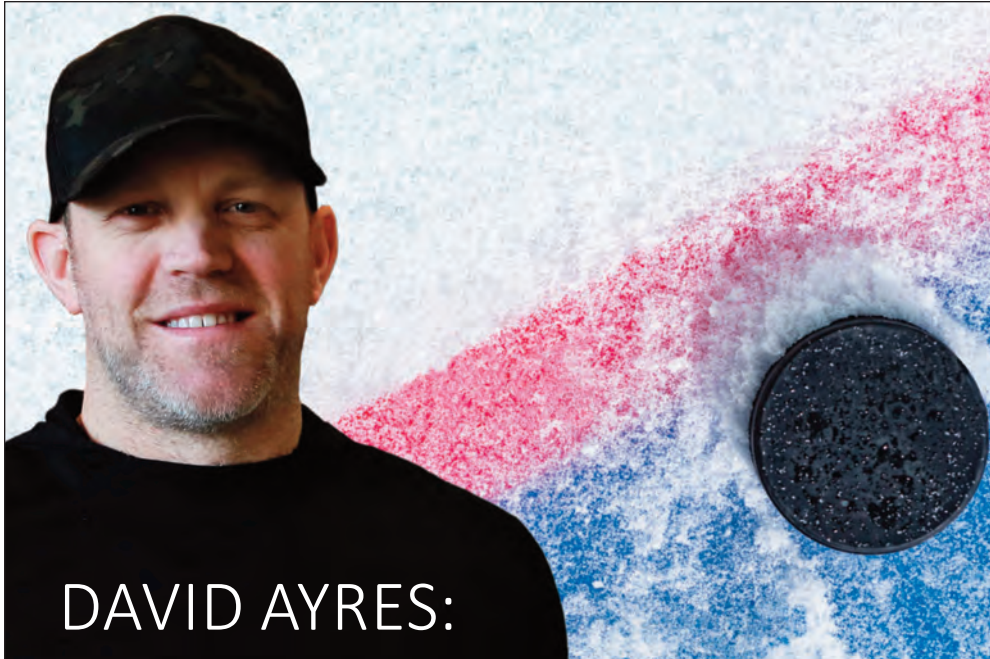
As the availability of vaccines against COVID-19 was announced, the question of who would receive it after first-responders were initially vaccinated was a widely debated topic. The Kidney Foundation began advocating at the provincial and territorial levels, in collaboration with the Canadian Society of Nephrology to prioritize those living with kidney disease.

Dr. Nickerson explains: “Both patients with end-stage kidney disease and those with kidney transplants are seen as being very vulnerable populations. We aggressively made the case in each provincial jurisdiction that these patients need to get top priority to get the vaccination.”

In addition to being immunocompromised and therefore at greater risk with COVID-19, in-centre dialysis patients cannot self-isolate. They must go to a dialysis unit three times a week and therefore needed to be prioritized to receive the vaccine, notes Dr. Suri.

The year 2020 was fraught with challenges and obstacles, but the kidney community can be proud of how it responded.

“A huge credit goes to our nurses, our social workers, our renal clerks, and all the people on the ground,” says Dr. Suri with gratitude. “The level of stress, especially in the first wave when we didn’t really know what we were doing and there were a lot of things going on at once – it was very stressful, yet everybody came through, so I’m quite proud of everybody.”



DAVID AYRES:

## A REAL GAME-CHANGER

Emergency goaltenders are seldom called upon to play in an NHL game. These players are not part of the home team or visiting team's regular roster. They are associated with the home arena and are asked to suit up when a team's regular and backup goaltenders are both unable to play.

On February 22, 2020, that's precisely what happened when the Carolina Hurricanes played against the Toronto Maple Leafs. At the age of 42, David Ayres was called upon to suit up for the Hurricanes in the second period. What's even more extraordinary is that David ended up the winning goalie; a feat that had never previously occurred in the NHL.

In the days and weeks that followed that fateful night, a media frenzy surrounded David. He was featured in the news and even appeared on American late-night television. That's when the public began to learn about his remarkable backstory: David's accomplishment was made even more astonishing when it was revealed that he was a kidney transplant recipient.

As an active and healthy 25-year-old, David was taken aback when he suddenly felt very weak during a round of golf. During a hospital visit, he was told he had high blood pressure, which had caused his kidneys to lose function. He later found out that the reverse was in fact true: his hypertension was a result of kidney failure.

So began dialysis treatments. Hockey helped see him through those sessions. His dialysis appointments were on Tuesdays, Thursdays, and Fridays – nights when there was always a hockey game on television. As the youngest patient in the dialysis unit, David always tried to keep things light and to put a smile on everyone's face, patients and nurses alike. He knew he had it comparatively easy after he discovered that others receiving treatments had been at it for over nine years.

David was lucky. His mother stepped forward to be a living donor. She underwent the required testing and, fortunately, was a match. The surgery wasn't without complications: David's heart stopped during the operation because of elevated potassium levels, but all turned out well. His recovery was slow. "It took a full year before I felt 100% myself again," Ayres recalls.

A few weeks following David's memorable NHL debut, the hockey season went

WITH DAVID'S HELP, THE KIDNEY FOUNDATION'S EMERGENCY FUND CAMPAIGN RAISED \$90,000, GREATLY EXCEEDING THE GOAL

sideways, as did just about everything else, because of the outbreak of the coronavirus.

The Kidney Foundation was introduced to David thanks to Saverina, a public relations professional specializing in sports who is currently awaiting a kidney transplant.

"I saw his story and reached out to his wife, Sarah, and I told her about my experience with kidney disease," she recalls. She has stayed in touch with the couple and helped David connect with The Kidney Foundation.

David already knew what it means to live with kidney disease. So, when he learned how much more difficult it had become for kidney patients because of the pandemic and the accompanying restrictions, he once again put his trademark determination to good use by making a different kind of save.


In March, The Kidney Foundation began experiencing a dramatic increase in demand for some of its services, including short-term financial assistance. In some parts of the country, it amounted to as much as 500% of the norm. Simultaneously, many of the Foundation's traditional fundraising events had to be either cancelled, postponed or re-invented as online events.

An emergency fund campaign was created to respond to these new circumstances. David volunteered to be the campaign's spokesperson, giving it a boost in visibility. It was a success that exceeded expectations.

"It was something I wanted to do as soon as I was asked," add David in conclusion. "It's something very close to my heart and I'm so happy we were able to raise money during a tough time to help so many people. I'm honoured to have been a part of it."

KIDNEY FOUNDATION 2020 KIDNEY WALKS

— FIRST EVER —  
**VIRTUAL  
KIDNEY WALKS**



105

VIRTUAL KIDNEY WALKS

1

IN-PERSON WALK

1

VIRTUAL BIKE RIDE

OVER  
19,000

DONORS

# A SHARED JOURNEY: THE ROAD TO MY TRANSPLANT



Dan and his wife Sharon  
(Photo: Danny Floh Back)

## Dan

IN FEBRUARY, 2020, DAN RECEIVED HIS SECOND KIDNEY TRANSPLANT. THE KIDNEY FOUNDATION HAS BEEN NEAR AND DEAR TO DAN SINCE HIS TEENS. HE HAS ATTENDED KIDNEY CAMP AND HAS VOLUNTEERED AS A SPOKESPERSON FOR THE FOUNDATION. HIS POSTS ON SOCIAL MEDIA CHRONICLED A COMPELLING STORY OF THE JOURNEY LEADING UP TO HIS SURGERY AS WELL AS HIS ARDUOUS RECOVERY DURING THE PANDEMIC. DAN'S SOCIAL MEDIA POSTS WERE DESIGNED TO KEEP HIS FAMILY AND FRIENDS INFORMED, BUT HE ALSO SAW IT AS AN OPPORTUNITY TO ENCOURAGE EVERYONE TO REGISTER TO BE ORGAN DONORS.



**Jun 4, 2013**

After 11 years, one month and 16 days being back on dialysis - just got the word - I am back on the transplant list as of today.



**July 6, 2016**

Big news. In October 2013, I was taken off the list when I was diagnosed with thyroid cancer. I had the thyroid glands removed in Feb 2014 and radiation therapy that April. Today, I got the news that, after getting the 2-year all-clear of cancer, I will be reactivated on the transplant list. Now in my 15th year of doing dialysis after losing my transplant of 17 years in 2002 (due to a cancer tumour in my kidney), it looks like there may be a glimmer of hope. Scared? You bet. Anxious? Check. Hopeful? Yes!



**1 day before surgery**

So, this morning I got a call I have been waiting for almost 18 years to receive. I have been called for a kidney transplant. Beginning the process now. Now, do me a favour, if you haven't signed up to be an organ donor, please give it some serious consideration and get 'er done. They are aiming for a 4:30 am tomorrow for surgery. It is not 100% go until it happens. Last cross-matching and organ condition assessment will be done. We won't know for sure until then. Deep breaths.



**2 days post surgery**

Surgery was a go the day before yesterday. On the operating table for over 8 hours. It was a difficult procedure, but they got it done. The transplanted kidney is in place, it just hasn't started working yet.



**6 days post surgery**

Tomorrow will be one week since the kidney transplant surgery. Kidney has not been working. Today I had a biopsy to see what the status is. My body is not rejecting the transplant. I am experiencing ATN (anti-tubular necrosis) which is the human body's way of protecting your kidneys when they experience severe trauma. They shut down to protect them from going into overdrive and killing you. So, all is good. We just have to wait for the kidney transplant to wake up.



**19 days post surgery**

Since returning home, there have been a few bumps in the road. I ended up back in the ER on Friday with my electrolyte levels all out of whack. The kidney was working overtime producing lots of urine and unfortunately also removing too much calcium and magnesium (hypercalcemia), which can be dangerous. So, they topped up my levels by IV and had me back home by 3 pm Saturday. Last night I woke up in excruciating pain in my lower left back and had to be brought back to the hospital by ambulance. There is a build-up of fluid pooling under the postoperative area and across my abdomen that is very painful and uncomfortable. Tomorrow, they will be surgically inserting a catheter into my lower abdomen to drain the fluid.





### 24 days post surgery

3½ weeks post-transplant and I am super immunosuppressed - it is mildly terrifying to be walking around knowing you are at much greater risk than almost everyone else. Meanwhile - to stay alive - you need to keep interacting with the medical / hospital system to get follow-up treatments, bloodwork, and medication adjustments.



### 25 days post surgery

Things are looking good. They have removed the 1st drain from my abdomen. No residual leakage. They have also removed 20 out of 40 alternating staples from the incision where kidney was put in.



### 29 days post surgery

Drainage tube has come partially out and there is quite a bit of fluid running everywhere. I'm in the ER now. Waiting to see the doctor. Had to send Sharon home. No visitors allowed past the reception area.



### 30 days post surgery

My wife Sharon is my heart, my everything. She has been my rock since I gave her the news that they had found a possible kidney for a transplant. She has been at the hospital every day, has spent more than a couple of nights in the ER and she has saved my life more than once when I almost bled out while on home dialysis. She is also immunosuppressed and puts herself at risk by bringing me a coffee and donut daily in the hospital, just to brighten my day. My heart broke seeing her leave last night and it broke into smaller pieces when I heard the news today that visitors were no longer allowed in the hospital. I understand why but I can tell you all that this is taking an emotional toll on the people stuck in the hospital. You can feel it in the air.



### 48 days post surgery

The function of the kidney transplant has been improving steadily. Unfortunately, post-surgical complications have not. I have been back in the hospital since Saturday. Unfortunately, they now must move to the last remaining option to deal with the issue: surgery. They will reopen up the area around the transplant to locate and hopefully correct the cause of the post-surgical complication. My years of internal scarring from many surgeries and several years on peritoneal dialysis is what will make this complex.



### 55 days post surgery

Still in the hospital. Kidney function remains good and strong. Surgery earlier in the week corrected what could have been a transplant-ending issue. It has been quite the experience to be at the centre of the storm on more than one occasion as Canada deals with the COVID 19 pandemic.



### 56 days post surgery

Good news! Going home today.



### 63 days post surgery

Today I reached the one week at home mark since being let out of the hospital. This is the longest time I have been home and out of hospital since the transplant. The good news is that the kidney appears to be functioning well and all the blood test results and levels are slowly moving in the right direction. Like a lot of people right now, I have my moments of the overwhelming kind of terror due to my health status and risk factor for COVID-19. On the really big change front - after doing dialysis at home for just over 18 years - they removed the dialysis machine from our house yesterday and tomorrow I will be having the staples removed from the last surgery. Looking forward to that.



### 151 days post surgery

5 months ago, I had my second kidney transplant after 18 consecutive years on dialysis. The recovery period has had its ups and downs with many challenges to overcome. Now, I am ready and excited to get back to work and begin having a meaningful and positive impact both in the world around me and on my students who I am lucky enough to spend time with as we find the way forward in navigating the new normal whatever it may be.



### 299 days post surgery

35 years ago today I had my first kidney transplant. Last year at this time, after 18 years back on dialysis, my wife and I had come to accept that I would in all likelihood never get another transplant and I would spend the rest of my life doing dialysis and dealing with a continued decline in my overall health and we would have to figure out how to cope and make the best of it. Little did we know that within a couple of months all of that would change. Stay strong and hold on - it may take longer than you would like, but don't give up. Change is inevitable and good things can happen when you least expect it.

#### KIDNEY FOUNDATION PROGRAMS



OVER **4,100** PEOPLE RECEIVED SHORT-TERM FINANCIAL ASSISTANCE

**\$519,000**

PROVIDED IN SHORT-TERM FINANCIAL ASSISTANCE

OVER **2,400** PEOPLE ACCESSED PEER-TO-PEER SUPPORT THROUGH **KIDNEY CONNECT**

# EMPOWERING TRANSPLANT PATIENTS AND CAREGIVERS

Navigating the healthcare system in Canada can be a challenge, even for those who are feeling well. Trying to find your way when facing something as complex as a transplant can seem impossible as people navigate a web of information, support, and resources. Throughout this journey, feeling empowered about decision-making, and being able to advocate for oneself can improve health and quality of life.

The Organ Donation Transplant Collaborative (ODTC) was introduced in 2018 by the federal government. Its mandate is to facilitate collaboration on an organ and tissue donation and transplantation system that gives Canadians timely and effective access to care.

Within the ODTC, the Patient/Advocate Advisory Committee (PAAC) was formed with the mission of recognizing and integrating lived experiences of donors and recipients from across the country into the ODTC's structure, work, and progress. This new committee brings together patient/advocates from all of the ODTC working groups and outside networks, and it will help unify and strengthen their voice across all areas of the Collaborative. The committee will also play an important role in ensuring adequate and relevant patient/advocate representation, including diversity considerations, in all working groups.

"With the ever-growing transplant waitlist and increasing complexity of our transplant population, it's vital that we develop a pan-Canadian organ donation and transplantation system that's responsive to the diverse needs of patients," says Kristi Coldwell, transplant recipient and PAAC co-chair.

Throughout 2020, PAAC members have been actively participating in every ODTC subcommittee in order to bring patient perspective to all facets of the organ and tissue donation process. They also have contributed to the content of a 2021 project called **Improving Engagement and**



**Empowering Patients Through Their Transplant Journey**, designed to reach out to many more patients and caregivers in two ways.

In order to provide information about the committee and its projects, and to build context and understanding of current patient journeys, a new section of The Kidney Foundation's website, located at [www.transplantjourney.ca](http://www.transplantjourney.ca), will provide a focal point for Canadians interested in the transplant journey. Visitors will have the opportunity to learn about the committee and its projects, improve their understanding of current patient journeys and be invited to have their say. The initial content will invite people to complete a survey about their own transplant journey. The survey will be available in English, French, Traditional Chinese, Simplified Chinese and Punjabi. Questions are designed to provide important information on the types of resources that were helpful and to identify gaps where more support is needed.

"It's so important that people know what resources and supports are available to them at every point in the transplant journey, otherwise we risk leaving people out and missing opportunities for transplant," says Shelby, a liver transplant recipient.

Further to the survey, a small group of patients and caregivers from different backgrounds and environments will meet regularly online to discuss their experiences in further detail, with a focus on how the system can be improved to better meet the needs of those on a transplant journey.

Throughout the project, a research team will be in close contact with the participants, working towards preparing a report to be published in 2022, which will outline the findings and provide patient-led and patient-focused recommendations for new policies, programs, and supports health systems should take into consideration.

"The report will be one of the many anticipated outcomes of the broader ODTC in its work to improve all facets of the transplant system in Canada from patient experience to data management to optimization of organ and tissue donation," says Lydia Lauder, PAAC co-chair and National Director of Programs & Public Policy for The Kidney Foundation of Canada.

"We hope to support patients and families as they're moving through their transplant journey and to develop recommendations that will improve the experience for all those who come after," adds Lauder. "The Kidney Foundation is committed to advocating for systemic changes that will improve outcomes and increase accessibility to organ donation as the preferred treatment method for so many."

## KIDNEY FOUNDATION EDUCATIONAL MATERIALS

**10,600**  
PATIENT HANDBOOKS  
DISTRIBUTED



**48,300**  
EDUCATIONAL BROCHURES  
DISTRIBUTED

# POLICY REMOVES OBSTACLES TO ORGAN DONATION

The Kidney Foundation of Canada has implemented a top-up Wage Replacement Policy for Living Organ and Tissue Donation that aims to remove barriers to organ donation by ensuring an employee's income remains unchanged throughout the process of making a living donation and for up to 15 weeks of recovery.

"We know just how transformative a kidney transplant can be," says Elizabeth Myles, The Kidney Foundation's National Executive Director. "The Foundation has always been a champion of organ donation, so this policy was a question of talking the talk and walking the walk."

Further to its new policy, The Kidney Foundation of Canada has been approved to join an elite group of organizations and businesses as a member of the Canadian Society of Transplantation (CST) Living Donor Circle of Excellence. The program was initially founded by the American Society of Transplantation.



"We encourage other Canadian organizations and companies to explore their own policies and to take a bold step to help those who so altruistically decide to dramatically improve the health of someone through the selfless act of organ donation," says Myles. "It is empowering for employees to feel supported throughout the process. From an employer's point of view, it was relatively easy to implement."

## Kidney Foundation Employee's Organ Donor Journey

Late last year, Geraldine was at home recovering from surgery. She was unable to work for six weeks. Unlike most major surgeries, though, Geraldine's was not brought about by a health condition of her own, nor was it a cosmetic procedure. It was following a selfless act of kindness and generosity. She elected to donate one of her healthy kidneys to someone living with kidney failure.

Geraldine is a registered nurse who spent most of her career taking care of kidney patients. During her tenure in several dialysis units, she gained firsthand knowledge of the devastation that can be caused by

kidney failure as well as the nearly full-time commitment required to manage it.

Since 2018, Geraldine has been working at The Kidney Foundation. Her role has been centred on awareness and prevention campaigns, as well as outreach with at-risk communities.

The idea of donating a kidney had naturally crossed her mind several times over the years, but the tipping point came when a family friend developed kidney failure. "He was really struggling with home dialysis because he lives in a remote rural area where the water quality wasn't always great,"

Geraldine recalls. "So, he wasn't always getting the best results from his dialysis."

Geraldine spoke at length with her family about the possibility of being a kidney donor. It was a decision to be arrived at together. Being an active person

in good health with good eating habits, she felt the time was right. However, her own health wasn't the only factor that had to be considered; there were also financial implications to be considered. Surgery and recovery would require a great deal of time away from work, and since Geraldine's husband is retired, they now rely on her income.

"Not only does [the recovery period] impact your income, but during the course of having your appointments and travelling to and from the facility to get your testing done before the surgery, you have to take time away from work, and that has a huge financial impact as well," observes Geraldine. She estimates that, during the year and a half leading up to the surgery, she had at least 20 days of tests. Additionally, she was required to self-isolate for 14 days prior to the surgery because of the pandemic.

Before telling the potential recipient of her decision and giving him false hope, she decided to contact her provincial transplant authority to find out if she could be tested as a possible match. Her first round of tests began in April 2019, but she didn't get the results until September. Despite not being blood relatives, Geraldine was a surprisingly good match.



GERALDINE AT THE KIDNEY FOUNDATION OFFICE

It was only then that the recipient was informed that a potential donor was found and who it was. Further testing took place for both and she met with her surgeon. They had hoped for a surgery date in February or March 2020, but the pandemic put them in a holding pattern. Having prepared herself physically and mentally, the delay was very disheartening.

Donor and recipient both breathed a sigh of relief, though, when the program eventually resumed and they were given a new surgery date in the fall. Geraldine was especially grateful because her daughter is expecting in the coming months and she wanted to be able to make a full recovery when the time came.

It only took a few weeks following surgery for Geraldine to feel 95% recovered, and her friend was also recovering well.

"The Kidney Foundation made the process really simple for me," says Geraldine with gratitude. "We're very fortunate to work for an organization that supports organ donation this way and I hope other employers will be inspired to develop similar policies to help improve donation rates."

## WHY CANADA NEEDS MORE ORGAN DONORS

3,400   
PEOPLE WAITING FOR  
A KIDNEY TRANSPLANT

3 YEARS   
8 MONTHS  
MEDIAN WAIT TIME FOR A  
DECEASED DONOR KIDNEY  
TRANSPLANT

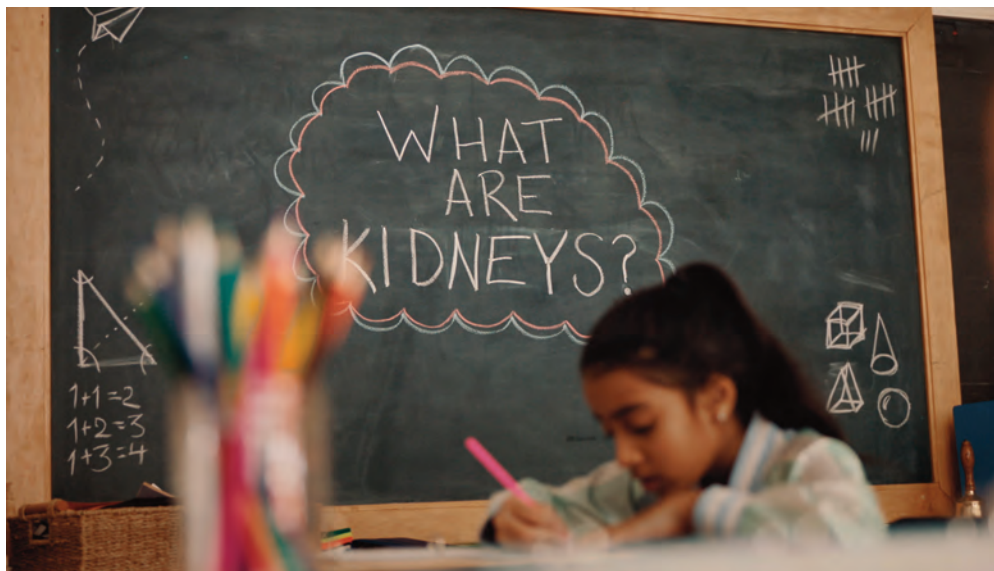
# MORE CANADIANS NEED TO KNOW KIDNEYS ARE VITAL

For those who have never been told to take better care of their kidney function, these small but mighty organs are an often-overlooked element of Canadians' health concerns.

As part of The Kidney Foundation of Canada's rebranding process in 2020, a new public service announcement and related key messaging was launched to illustrate some of the common, and some of the more unusual, misconceptions about kidneys. The television and social media campaign, although lighthearted and funny, with school children trying to explain what kidneys do, delivers an important message. Kidneys are vital to overall health.

A 2019 Ipsos Reid poll for The Kidney Foundation revealed that six in 10 Canadians interviewed said they did not know anything about kidney disease. Fewer than four in 10 knew that there is no cure for kidney disease.

"Awareness helps more Canadians to understand the dramatic effect that kidney disease and poor kidney health management can have on our overall health outcomes," says Elizabeth Myles, National Executive Director. "A diagnosis of kidney failure changes someone's life forever. Kidney failure means a lifetime of often difficult dialysis treatments that are continuous unless the person is fortunate to have a kidney transplant, which is the optimal treatment option."



Increasing awareness of the kidneys' vital role provides The Kidney Foundation with the opportunity to introduce people to high-quality educational materials and supports which may help them or someone they love throughout their diagnosis and treatment.

Poll results find that "while a strong majority of Canadians have a general understanding of what kidneys do, a minority can provide an explanation of what kidney disease is. Nearly one-half of Canadians do not know if they are personally at risk for kidney disease."

HUMOUR WAS USED TO HIGHLIGHT MISCONCEPTIONS ABOUT WHAT KIDNEYS REALLY DO AND CANADIANS WERE ENCOURAGED TO GET THE FACTS

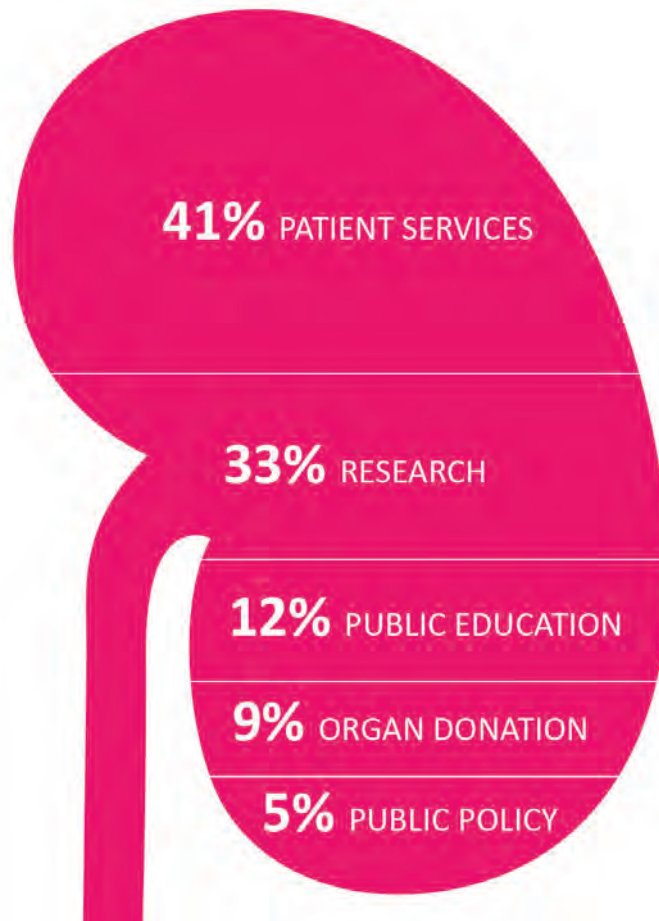
With the launch of the awareness campaign, the Foundation encourages Canadians to visit its updated risk awareness tool at [kidney.ca/risk](http://kidney.ca/risk). The interactive tool asks Canadians common questions about their overall health and helps to identify potential risks for kidney health. "The risk awareness tool, which will also soon be available in Chinese and Punjabi, encourages people to save the results and use them to spark conversation with their primary health care providers, so they know if they need to take any steps to improve kidney health," says Lydia Lauder, National Director of Programs & Public Policy.

Education and awareness remain a pillar of The Kidney Foundation's mission. More than 25% of those who see a nephrologist for the first time must commence dialysis within 90 days because they do not know their kidneys have failed. A better understanding of kidney health and of the risk factors associated with kidney disease can help people to be diagnosed early so that they can prolong or preserve their kidney function and delay the need for dialysis.



# SPENDING BY PROGRAM

Thanks to generous donor support, The Kidney Foundation's program investments help to assure improved kidney health for all, greater supports and services for people impacted by kidney disease, and bring us closer to a cure. Strategic investments in fundraising, administration and management serve to further support the fulfillment of our mission.



## KIDNEY FOUNDATION ONLINE ENGAGEMENT



**724,200**  
WEBSITE USERS



**5,000**  
WEBINAR VIEWS



**69,200**  
TOTAL SOCIAL  
MEDIA FOLLOWERS  
(ALL PLATFORMS)



**82,800**  
NEWSLETTER SUBSCRIBERS  
(PRINT & ELECTRONIC)

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Charitable Registration Number: 10756 7398 RR0001  
The Kidney Foundation of Canada's audited financial  
statements are available online at [www.kidney.ca/about-us](http://www.kidney.ca/about-us)



**kidney**  
FOUNDATION™

**Impacts & Outcomes**  
**of kidney research**  
**in Canada**

**Dr. Christopher Kennedy**

2020 Recipient of the

Dr. John B. Dossetor Research Award

## COVID-19 AND ITS IMPACT ON RESEARCH

Like most everything else, COVID-19 had a significant impact on research and researchers in Canada. Labs were closed and many research competitions were paused or stopped. Health charities like The Kidney Foundation significantly support Canada's research ecosystem, contributing up to \$155 million annually. These same charities have faced up to a 50% decrease in revenues due to the COVID-19 pandemic, resulting in a potential \$103 million shortfall for research funding.

The Kidney Foundation and its research program were also impacted significantly by the pandemic. In consultation with our Research Council, we made the difficult decision to pause research grant payments for three months during the first wave of the pandemic to ensure business continuity and meet all our research commitments. We also delayed the start of payments for new grants by the same time period. We reduced the number of new grants awarded in competitions that hadn't yet been peer reviewed and negotiated postponement of some commitments with our research partners.

Through these efforts we managed to trim \$1 million from our research budget without significantly reducing our support of the research community.

In addition, in response to the pandemic, we partnered with other health charities to advocate for emergency funding to support health research. Many in our research community responded very positively, adding their signatures to a letter sent to the federal government.

At The Kidney Foundation, our commitment to funding research to improve patient outcomes and find a cure is a founding principle and remains a top priority. Despite the challenges presented by a global pandemic, the Foundation remains firmly committed to fulfilling all research commitments and to maintaining the highest priority on research investment.

In addition to providing support to 103 research grants in 2020 and awarding \$3.27 million to new research initiatives starting in 2020, we remain key partners in national research initiatives such as

Can-SOLVE CKD and the Canadian Donation and Transplantation Research Program (CDTRP). We have also partnered with the Canadian Institutes of Health Research on a new initiative to provide \$2 million to fund much-needed research into diabetic kidney disease.

In 2020, we launched our research strategy which focuses on investing in stakeholder-identified priorities, supporting innovative and transformational opportunities, and building the evidence base on impacts and outcomes of kidney health and disease research.

Moving into 2021 and beyond, The Kidney Foundation is committed to ensuring that our researchers can continue their vital work to improve the lives of people affected by kidney disease.



*Elizabeth Myles*

**Elizabeth Myles,**  
National Executive Director



*Leanne Stalker*

**Leanne Stalker,**  
National Director of Research

### RESEARCH INVESTMENTS MADE IN 2020:



**\$2,554,618\***

\* Includes funding of commitments made in prior years and other support investments



## DR. KENNEDY AT THE HELM OF NEW AND PROMISING RESEARCH

His recent study offers an important step forward  
in our understanding of diabetic kidney disease

Dr. Christopher Kennedy is a world leader in kidney research whose work is helping us better understand the causes of kidney damage. He is a Senior Scientist at the Ottawa Hospital Research Institute and a Professor in the Faculty of Medicine at the University of Ottawa. For the past 20 years, he has focused his attention on the complex workings of the kidney and the tiny glomeruli that play such a vital role in its function.

“The kidney is a fascinating organ because it is so complicated,” Dr. Kennedy says. “I think that trying to understand the kidney is a real challenge. It has so many different cell types and so many functions and roles.”

After finishing graduate studies at the University of Ottawa, Dr. Kennedy began his postdoctoral training at Vanderbilt University in Nashville. There, he focused on the role of prostaglandins in renal disease progression as a fellow of the National Kidney Foundation, in the Division of Nephrology. He recalls his time at Vanderbilt as “a real privilege”. It was an opportunity to learn from some of the brightest minds in kidney research from around the world, and become immersed in nephrology culture.

Returning to Ottawa, Dr. Kennedy set up a research program which has earned international recognition for its groundbreaking work. Most recently, his team has examined the role of an enzyme that lab evidence has found damages kidney filters.

“The study focuses on an enzyme called Nox5,” Dr. Kennedy explains. “It is part of a family of enzymes that take oxygen and

convert it into what we call a reactive oxygen species. You need a certain amount of these enzymes in your body to ward off infection, but it is important to have the right balance.”

When there are too many Nox5 enzymes circulating, the reactive oxygen they produce



can damage healthy cells. His research team has found that Nox5 plays a critical role in contributing to diabetic kidney disease.

“Does introducing the Nox5 gene make kidney disease such as diabetic kidney disease worse in the mouse? The short answer is ‘yes, it does.’ Our study provides fairly good evidence that if you have too much of this enzyme, that is not a good thing.”

Dr. Kennedy’s team has also discovered which factors can activate and deactivate the Nox5 enzyme. The ultimate goal is to build on this

evidence and to develop new treatments to prevent or slow down kidney disease in people with diabetes and high blood pressure. This research is especially relevant today, as an increasing number of Canadians are diagnosed with diabetes, the leading cause of kidney failure in Canada. Up to one half of people with diabetes will show signs of kidney disease in their lifetime.

Dr. Kennedy has received funding from the Canadian Institutes of Health Research, The Kidney Foundation of Canada and the Canada Foundation for Innovation. He also serves on a number of advisory boards and committees. In 2020, Dr. Kennedy was the recipient of the Dr. John B. Dosseter Research Award, for outstanding service to The Kidney Foundation’s research program. He says The Kidney Foundation of Canada has provided vital funding to get his research projects off the ground.

“The Kidney Foundation of Canada has been instrumental in keeping smaller projects going, which then merge and eventually bloom into much larger projects. They have supported my research for over 20 years.”

What he finds most fulfilling about his work are those ‘wow’ moments when new data comes in, that lead to a breakthrough. He acknowledges that doesn’t happen too often in research, where you have a lot of misses and frustrations.

“I always tell my students, 90 per cent of the stuff you are going to do is not going to work. It is the 10 per cent that really keeps you coming back.”

# GENE THERAPY SHOWS PROMISE FOR TREATMENT OF FABRY DISEASE

Through a pilot study partially funded by The Kidney Foundation, five Fabry disease patients were treated at Alberta Health Services' Foothills Medical Centre in Calgary, Princess Margaret Cancer Centre, Toronto, and Nova Scotia Health's Queen Elizabeth II Health Sciences Centre in Halifax with gene therapy. The findings, published in the *Nature Communications* journal, are very encouraging.

Fabry disease is a rare genetic disorder in which a mutated gene leads to a loss or reduction of the body's production of a particular enzyme that breaks down a fatty material, the buildup of which leads to problems within the heart, kidneys, and other tissues.

Features of Fabry disease include fatigue, diarrhea, heart failure, strokes, kidney disease, skin rash, and nerve pain. Currently, the most common form of treatment is intravenous enzyme replacement therapy administered every two weeks. Alternatively, chaperone therapy, a molecular therapy taken orally helps to preserve the enzyme activity. This treatment is only effective for certain genetic mutations, so just 25% of Canadian Fabry patients are eligible. Both therapeutic options are costly and are required for the patient's lifetime.

Dr. Michael West, a nephrologist and Nova Scotia Health co-investigator of the gene therapy study in Halifax, explains that a therapeutic gap exists in the treatment of Fabry disease. Neither enzyme replacement therapy nor chaperone therapy is a cure; patients are still at risk of kidney failure, strokes, cardiomyopathy, and other complications, albeit to a lesser degree.

The principal investigator in this study, Dr. Jeffrey Medin, MACC Fund Professor at the Medical College of Wisconsin and Affiliate Scientist at University Health Network in Toronto, is one of the pioneers of gene therapy for the treatment of the disease. His early work with gene therapy for Fabry disease in animals dates back to the 1990s.



DR. MICHAEL WEST, NEPHROLOGIST AND  
NOVA SCOTIA HEALTH CO-INVESTIGATOR

Gene therapy uses a lentiviral vector to add DNA into cells. The lentivirus is first rendered inactive by removal of the viral DNA, then DNA that codes for the normal human enzyme is added. "The virus will quite efficiently 'infect' human cells, in other words, transmit the new DNA into the host cell DNA, which allows cells to make normal enzymes," explains Dr. West. Prior to the therapy, patients donated blood stem cells to which the Lentiviral vector was then added. They then received a single dose of

chemotherapy, which is used routinely for stem cell transplants to make room in the bone marrow for the stem cells to engraft and produce daughter cells. The transfected cells were then infused into the patients through a peripheral IV which was performed on an outpatient basis. Regular blood work was done to monitor the patients following the procedure.

In this first-ever gene therapy trial for Fabry disease, the patients involved were followed from January 2017 to February 2020. Their follow-up will continue until February 2024.

"We were able to show that the amount of enzyme that the patient made started to go up by day 12," states Dr. West. "It continued to rise in all five patients and stayed that way so that they were all well above the baseline level that they had previously." Three of the five patients were able to stop their intravenous enzyme replacement therapy.

The primary goals of the study were to investigate the feasibility and safety of gene therapy treatment for Fabry disease. The study did not find any untoward safety events arising from the treatments. Furthermore, notes Dr. West, the treatment could prove to be less costly than those currently available.

"I wouldn't go so far as to say this is a cure for these patients," cautions Dr. West. "But it may turn out to be a better way to provide enzyme therapy 24/7 to these patients as opposed to just giving it once every two weeks."

"We are very pleased that this worked and we're very appreciative of funding from The Kidney Foundation," concludes Dr. West.

# LEADING EFFORTS TO BETTER UNDERSTAND KIDNEY REJECTION AND FIBROSIS AFTER TRANSPLANT

For Dr. Ana Konvalinka, one of the most satisfying aspects of research is being part of a scientific team, working together to solve puzzles. In nephrology there are many unknowns to explore. Her lab in Toronto is guided by a central question: What can we do to heal kidneys so they will work better for longer?

“All of my research endeavors have been motivated by unmet clinical needs. There are enormous unmet clinical needs in nephrology,” Dr. Konvalinka says. “Probably the biggest ones have to do with improved therapies to arrest the progression of kidney disease and prevent premature kidney graft loss.”

Dr. Konvalinka is a nephrologist and clinician scientist at the University Health Network in Ontario. She is also an Assistant Professor at the University of Toronto. After completing her medical degree at the University of Ottawa in 2003, she studied internal medicine and nephrology in Toronto, and earned a PhD in basic science.

It was during her nephrology residency training that Dr. Konvalinka decided to pursue research in an effort to find new ways to fight kidney disease. She completed clinician-scientist training and began her career as a principal investigator in 2015. Her very first research grant was from The Kidney Foundation of Canada.

“The Kidney Foundation of Canada biomedical research grant was my first official grant, and it cemented my confidence and provided me with the necessary funds to keep going,” she says, noting that she received a Kidney Foundation Biomedical Research Grant and KRESCENT new investigator grant the same year. The KRESCENT grant, she adds, was equally important for its training and opportunities for professional networking and collaboration.

Furthermore, through a special research project grant from the Foundation to study predictive biomarkers, her lab is working to examine potential markers of early kidney graft fibrosis in the transplanted organ. “For those two reasons, The Kidney Foundation of Canada has played an absolutely fundamental role in any success I may have in the future.”



DR. ANA KONVALINKA

Dr. Konvalinka’s main clinical and research interests are in antibody-mediated rejection, which is the leading cause of the premature loss of transplanted kidneys. Her lab is working to better understand the specific ways antibodies cause donor kidney rejection and injure tissue in the transplanted organ. They are looking to identify how these antibodies interact with immune cells in the blood and in the tissue. The goal is to design better and more personalized treatments for patients and have donor kidneys last longer in transplant recipients.

Currently, she notes, living donor kidneys in her transplant program stay functional for about 20 years on average while a kidney from a deceased donor usually lasts about 12-15 years.

“You can imagine that a young person who has to have renal replacement therapy will inevitably have multiple transplants in their lifetime,” Dr. Konvalinka says. “The function of those transplants will ultimately be impaired because of mostly scarring and antibody-mediated rejection. We are looking at ways to have the kidneys last longer, so each patient could have one kidney transplant for life.”

Medical research is often incremental, but Dr. Konvalinka’s lab has made some exciting progress. Her research compared the kidneys of patients who had antibody-mediated rejection to patients with other forms of kidney injury. The result was a significant discovery. Dr. Konvalinka found there were some unexpected and very early changes in the tissue that surrounds and supports the cells in the kidney of those who developed antibody-mediated rejection.

“This is very important because you usually see these types of alterations very late in chronic disease when changes are irreversible,” Dr. Konvalinka notes. “Nobody previously showed that these changes can actually begin to happen early and nobody really knows what causes them. So, we are beginning to study why they happen so early and how we can reverse them.”

She hopes the discoveries they make in the lab will later translate into clinical studies and new treatments to slow down, or even reverse kidney damage. The ultimate goal is to improve patient outcomes, so people living with kidney disease can be offered a better quality of life in the years ahead.

## IDENTIFYING THE GENETIC CAUSES OF ATYPICAL POLYCYSTIC KIDNEY DISEASE



### DR. YORK PEI

Polycystic kidney disease (PKD) is a genetic disorder that triggers multiple cysts to form in the kidneys. It is also one of the leading causes of advanced kidney failure.

Autosomal dominant polycystic kidney disease (ADPKD) is the most common inherited cause of PKD and is generally diagnosed by an ultrasound scan when a family history exists. However, up to

25% of patients with PKD do not have a positive family history of ADPKD, display abnormal kidney imaging patterns, or are tested negative for PKD1 and PKD2 mutations which account for most of the cases of ADPKD; these patients are said to have atypical PKD. Identifying the origin of atypical PKD in any given patient (i.e., isolating the specific gene mutations) can be expensive and time-consuming as it requires the screening of multiple genes beyond those involved in ADPKD.

Additionally, some people with atypical PKD may have a condition called “somatic mosaicism” whereby organs and tissues are comprised of both normal and mutated cells due to an impacted stem cell during embryo development.

Dr. York Pei and his team of investigators are using next generation sequencing (NGS) – a new technology that provides comprehensive mutation screening of multiple genes at a modest cost – to determine the genetic causes of a cohort of patients with atypical PKD. A promising tool that is revolutionizing novel disease gene discovery, NGS also delivers an in-depth analysis of DNA sequencing patterns that facilitates the detection of mosaic mutations. Dr. Pei is hopeful his research will accelerate the advancement of cost-effective molecular diagnostic training and ultimately lead to ground-breaking treatments for PKD.

### WHAT THIS MEANS FOR PATIENTS:

Next generation sequencing will allow researchers to recognize specific gene defects in PKD biology and develop targeted therapies to prevent patients’ progression to kidney failure.

## IMPROVING KIDNEY CARE USING PATIENT-RELATED OUTCOMES



### DR. KARA SCHICK-MAKAROFF

There is international interest on the use of patient-reported outcomes and experience measures (PROs) in kidney care. PROs are recognized as a means for patients to provide information about their quality of life (e.g., well-being, overall health, symptoms, functional status and other aspects of psychological, social, and spiritual quality of life) and experiences with care. Currently, there is

a knowledge gap in our understanding of how PROs are optimally used in nephrology care. The purpose was to study the use of PROs for improving person-centred care at individual (e.g., patients, caregivers, providers) and combined (e.g., government, policy, system) levels of health care decision making. The study included pre-dialysis care, dialysis, pediatric kidney disease, and kidney transplantation. Dr. Schick-Makaroff looked at the literature using an approach called “realist synthesis.” Her searches identified 19,961 texts; 84 theory and 34 research texts were used.

PROs are intended to be useful for providing person-centred kidney care through three types of use. The first type is use of individual-level PRO data for patient care. This first type had the largest amount of literature exploring the topic. Clinician use to support

person-centred care, and patient use to support patient engagement, are meant to improve patient satisfaction, health and quality of life. Electronic collection may support efforts towards these goals. The second type is combined PRO data, which may be publicly reported, to inform decisions in patient care. And the third type is organizational use of combined PRO data, including publicly available PRO data to compare dialysis centres. Both the second and third types of PRO use include pressures that may trigger plans to improve the care provided to kidney patients. While the second and third types are important in many national kidney programs, they have minimal research support.

This work was presented at conferences and published in the journals *BMC Systematic Review* and *International Journal of Qualitative Methods*.

Dr. Schick-Makaroff and her team are working toward dissemination (in articles) and synthesizing findings into 2-3-minute whiteboard videos, one for patients and one for clinicians, which will be posted on [www.healthyqol.com](http://www.healthyqol.com)

### WHAT THIS MEANS FOR PATIENTS:

The findings from this synthesis will provide a framework to guide both policy makers and health professionals on how to enhance person-centered care through successful use of PROs across individual and health system levels in nephrology.

## USING STRENGTH-BASED APPROACHES TO IMPROVE KIDNEY HEALTH FOR CANADA'S INDIGENOUS POPULATIONS



### DR. MARY SMITH

Indigenous people residing in Canada's northern communities often struggle with dialysis and awaiting transplants due to their remote location. Having to travel long distances to receive treatment is costly and creates long and exhausting days. While transplants are performed, the need for more is an ongoing challenge as well as sustaining dialysis and supports within the home or community.

Dr. Mary Smith and her team are working towards expanding kidney health for First Nations, Métis and Inuit populations across the country using holistic and strength-based approaches that encourage communities to come together to address culturally safe solutions directed at improving overall quality of life. Prior to COVID-19, an advisory committee comprised of Indigenous community members with kidney disease from Ontario's North Simcoe Muskoka area met regularly. Together, the committee and research team collaborated on initiatives aimed at promoting learning and recognition of the regional interplay between geography, history and culture in relation to contemporary experiences within health care and health care education.

Through sharing circles where traditions and culture as protocols are honoured, the committee identified strategies to not only foster kidney health and the prevention of kidney disease, but also increase kidney donation and transplantation, and promote accessible dialysis. An Elder resident participant was also appointed to further connections between Indigenous communities. Despite the transition to virtual meetings and teleconferencing during the pandemic, talks continued and novel ideas emerged, including the creation of an online support group.

By raising awareness of indigenous people's needs via a robust community-driven effort, Dr. Smith and her team believe that locally contextual focused solutions to kidney health-related issues can be achieved in tandem with the broader medical system, thereby contributing to enhanced care for these kidney patients and their families.

### WHAT THIS MEANS FOR PATIENTS:

Active participation by Indigenous people in every phase of this project will not only help integrate the importance of their ways of being and knowing into research design, but also lead to better future representation of communities, while ultimately improving kidney health and facilitating access to life-saving treatments.

## EXPLORING FRAILTY AMONG PATIENTS AWAITING A KIDNEY TRANSPLANT



### DR. KARTHIK TENNANKORE

Every year, the number of people in need of a kidney transplant continues to grow due to a shortage of available organs. Currently, Canada has general guidelines regarding eligibility criteria for transplant waiting lists. While a detailed evaluation of an individual's health is part of protocol, researchers are exploring the effects of frailty – any difficulty in function, fitness and

activity – on outcomes for kidney patients awaiting a transplant and post-transplant.

Using different tools to measure frailty among people living with kidney disease in centers across Nova Scotia, New Brunswick, Quebec, Ontario and Saskatchewan, Dr. Karthik Tennankore and his team of investigators are examining the influence of frailty on the health of patients waiting for a kidney transplant, as well as the risk of early kidney graft loss after transplant. Frailty is often associated

with negative consequences following a kidney transplant, such as risk for a shortened lifespan. By providing transplant specialists with a more complete picture of a person's overall health that complements the tests already being used, Dr. Tennankore's research aims to reinforce objective decision-making about eligibility and better inform patients seeking to be put on a kidney transplant wait list. Additionally, it is an important measure before efforts can be made to mitigate frailty so that individuals will be healthier at the time of their surgery.

Through a greater understanding of frailty's impact, Dr. Tennankore is hopeful this study will be the first step towards a national, standardized evaluation of a patient's function, fitness and activity when being considered for a kidney transplant.

### WHAT THIS MEANS FOR PATIENTS:

The identification of individuals at risk of health issues while awaiting a kidney will result in closer monitoring and timely interventions to improve their condition prior to transplant while optimizing outcomes post procedure.

# 2020 NEW FUNDED RESEARCHERS BY PROGRAM

Impacts & Outcomes  
of kidney research  
in Canada

## KIDNEY HEALTH RESEARCH GRANTS



**DR. MOHSEN AGHARAZII**  
**Co-Applicant:** Richard Larivière  
 Université Laval, QC  
 2020-2022: \$120,000  
**Project Title:** Accelerated CKD-related vascular calcification: side effects of diuretics drugs  
**Category:** Hypertension



**DR. XING-ZHEN CHEN**  
 University of Alberta, AB  
 2020-2022: \$120,000  
**Project Title:** Discovering new therapeutic targets for polycystic kidney disease  
**Category:** Kidney Biology



**DR. MÉLANIE DIEUDÉ**  
**Co-Applicant:** Héloïse Cardinal  
 Université de Montréal, QC  
 2020-2022: \$120,000  
**Project Title:** Mechanisms of injury to renal microvessels triggered by anti-LG3 responses in the autoimmune disease lupus nephritis  
**Category:** Predictive Biomarkers



**DR. MARIE-CHANTAL FORTIN**  
**Co-Applicants:** Christy Simpson, Istvan Mucsi, Jagbir Gill, Marie Achille, Shaifali Sandal  
 Centre Hospitalier de l'Université de Montréal, QC  
 2020-2022: \$79,346  
**Project Title:** Studying stakeholders' perspectives on ethical and logistical issues related to advanced and voucher donation in kidney transplantation in Canada  
**Category:** Transplantation



**DR. LAKSHMAN GUNARATNAM**  
**Co-Applicant:** Elena Tutunea-Fatan  
 University of Western Ontario, ON  
 2020-2022: \$120,000  
**Project Title:** Role of kidney injury molecule-1 in the acute kidney injury to chronic kidney disease transition  
**Category:** Renal Failure



**DR. DYLAN BURGER**  
**Principal Applicant:** Marcel Ruzicka  
**Co-Applicant:** Brendan McCormick  
 Ottawa Hospital Research Institute, ON  
 2020-2022: \$118,012  
**Project Title:** Sex differences in platelet microparticles in chronic kidney disease patients on dialysis  
**Category:** Dialysis



**DR. EMMANUELLE CORDAT**  
 University of Alberta, AB  
 2020-2022: \$120,000  
**Project Title:** Understanding the role of claudin-4 in calcium balance to find therapies for kidney stones  
**Category:** Water/Salt and Calcium Handling by the Kidney



**DR. MEGHAN ELLIOTT**  
**Co-Applicants:** Braden Manns, Juli Finlay, Kara Schick-Makaroff, Maoliosa Donald, Maria Santana  
 University of Calgary, AB  
 2020-2022: \$120,000  
**Project Title:** Promoting the patient voice: understanding the implementation of patient-reported outcome measures in hemodialysis care  
**Category:** Dialysis



**DR. PAUL GOODYER**  
 The Research Institute of the McGill University Health Centre, QC  
 2020-2022: \$120,000  
**Project Title:** New therapy for a rare form of hereditary kidney stone disease, cystinuria  
**Category:** Genetics



**DR. PAUL ISENRING**  
 Université Laval, QC  
 2020-2022: \$120,000  
**Project Title:** Understanding the mechanisms by which salt, acid base balance and blood pressure is regulated in the kidney  
**Category:** Water/Salt and Calcium Handling by the Kidney



**DR. ANDREY CYBULSKY**  
 The Research Institute of the McGill University Health Centre, QC  
 2020-2022: \$120,000  
**Project Title:** Studying the dis-regulation of protein kinase SLK that leads to glomerulonephritis  
**Category:** Glomerulonephritis



**DR. JOAN KREPINSKY**  
 McMaster University, ON  
 2020-2022: \$120,000  
**Project Title:** Role of Lasp1 in the pathogenesis of diabetic kidney disease  
**Category:** Diabetes



**DR. YORK PEI**  
 Toronto General Hospital, ON  
 2020-2022: \$120,000  
**Project Title:** Improving diagnosis of atypical polycystic kidney disease by next generation sequencing  
**Category:** Genetics



**DR. SAMUEL SILVER**  
**Co-Applicants:** Abhijat Kitchlu, Amber Molnar, Edward Clark, Oleksa Rewa, Ron Wald, William Beaubien-Souligny  
 Queen's University, ON  
 2020-2023: \$178,279  
**Project Title:** Promoting kidney recovery after acute kidney injury receiving dialysis  
**Category:** Renal Failure

## ALLIED HEALTH KIDNEY RESEARCH GRANT



**DR. SAMANTHA ANTHONY**  
**Co-Applicants:** Istvan Mucsi, Kenneth Fung, Linda Wright, Paula Neves, Rulan Parekh, Susan Abbey  
 The Hospital for Sick Children, ON  
 2020-2022: \$120,000  
**Project Title:** Improving health equity: Access to living donor kidney transplantation  
**Category:** Transplantation



**DR. JAMES LAN**  
**Co-Applicants:** Amanda Jean Vinson, Frans Claas, Gonca Karahan, Howard Gebel, Jagbir Gill, John Gill, Kathryn Tinckam, Paul Keown, Raymond Ng, Robert Bray, Robert Liwski, Sebastian Heidt  
 University of British Columbia, BC  
 2020-2022: \$119,560  
**Project Title:** Improved laboratory tests for kidney recipients to optimize transplantation  
**Category:** Transplantation



**DR. JANUSZ RAK**  
**Co-Applicants:** Pouria Jandaghi, Yasser Riazalhosseini  
 The Research Institute of the McGill University Health Centre, QC  
 2020-2022: \$120,000  
**Project Title:** Investigating cancer cell metabolism and tumor microenvironment to discover new treatment options for kidney cancer  
**Category:** Cancer



**DR. MANISH SOOD**  
**Co-Applicants:** Daniel Schwartz, Doug Manuel, Emily Rhodes, Juan-Jesus Carrero-Roig, Keiichi Sumida, Marcello Tonelli, Min Jun, Navdeep Tangri  
 Ottawa Hospital Research Institute, ON  
 2020-2022: \$111,967  
**Project Title:** Development, validation and dissemination of a survey-based prediction equation targeting the general public: PREDICT-CKD Lifestyle  
**Category:** Screening & prevention of renal disease

## ALLIED HEALTH KIDNEY DOCTORAL FELLOWSHIP



**PENNY JARRIN**  
**Supervisor:** Christopher McIntyre  
 University of Western Ontario, ON  
 2020-2022: \$58,000  
**Project Title:** Improving hemodialysis tolerability through innovation  
**Category:** Dialysis



**DR. FABRICE MAC-WAY**  
**Co-Applicants:** Darren Richard, Nicolas Bertrand  
 Université Laval, QC  
 2020-2022: \$120,000  
**Project Title:** Nanoparticles to understand and treat vascular calcification in chronic kidney disease  
**Category:** Hypertension



**DR. YASSER RIAZALHOSSEINI**  
**Co-Applicants:** Janusz Rak, Kate Glennon, Simon Tanguay  
 McGill University, ON  
 2020-2022: \$119,996  
**Project Title:** Harnessing non-invasive liquid biopsy information for sex-appropriate management of renal cancer  
**Category:** Cancer

## ALLIED HEALTH KIDNEY SCHOLARSHIP



**KELLY PICARD**  
**Supervisor:** Caroline Richard  
 University of Alberta, AB  
 2020: \$5,000  
**Project Title:** Nutrition in CKD patients  
**Category:** Nutrition

## CDTRP PARTNERSHIP INNOVATION GRANTS



**DR. LAKSHMAN GUNARATNAM**

University of Western Ontario, ON  
2020-2022: \$30,000

**Project Title:** New therapy to improve renal transplant outcomes

**Category:** Transplantation



**DR. DARREN YUEN**

St. Michael's Hospital, ON  
2020-2022: \$30,000

**Project Title:** Nanobubbles: a new way to non-invasively measure donor kidney ischemia-reperfusion injury

**Category:** Transplantation

KRESCENT IS A NATURAL PARTNERSHIP OF THE KIDNEY FOUNDATION, THE CANADIAN SOCIETY OF NEPHROLOGY AND THE CANADIAN INSTITUTES OF HEALTH RESEARCH INSTITUTE OF NUTRITION, METABOLISM AND DIABETES.

## KRESCENT POST-DOCTORAL FELLOWSHIPS



**DR. MALLORY DOWNIE**

**Supervisors:** Robert Kleta; Rulan Parekh  
University College London, UK  
2020-2022: \$65,000

**Project Title:** Using genetics for precision medicine in nephrotic syndrome

**Category:** Genetics



**DR. HARMANDEEP KAUR**

**Supervisor:** Andrew Advani  
St. Michael's Hospital, ON  
2020-2023: \$82,500

**Project Title:** Reshaping epigenetics to improve outcomes after acute kidney injury

**Category:** Acute kidney injury

## RESEARCH BY THE NUMBERS

**\$3,273,000** IN RESEARCH GRANTS AWARDED IN 2020\*

**103** GRANTS FUNDED

**414** RESEARCHERS SUPPORTED



IN 2020,  
THE KIDNEY FOUNDATION  
PROVIDED FUNDING TO:

**62** BIOMEDICAL RESEARCH GRANTS **123** COLLABORATORS

**26** KRESCENT AWARDS **24** SUPERVISORS

**10** ALLIED HEALTH KIDNEY AWARDS **31** RESEARCH INSTITUTES

**107** PRINCIPAL APPLICANTS **8** PROVINCES

**160** CO-APPLICANTS **5** PARTNERSHIPS IN LARGE NETWORKS



RESEARCH THEMES  
FUNDED IN 2020:

|                        |  |
|------------------------|--|
| ACUTE KIDNEY INJURY    | NUTRITION                                      |
| CANCER                 | ORGAN DONATION                                 |
| CHRONIC KIDNEY DISEASE | PREDICTIVE BIOMARKERS                          |
| DIABETES               | QUALITY OF LIFE                                |
| DIALYSIS               | RENAL FAILURE                                  |
| GENETICS               | SCREENING & PREVENTION OF RENAL DISEASE        |
| GLOMERULONEPHRITIS     | TRANSPLANTATION                                |
| HYPERTENSION           | UROLOGY  |
| KIDNEY BIOLOGY         | WATER, SALT AND CALCIUM HANDLING BY THE KIDNEY |
| KIDNEY DEVELOPMENT     |  |



**DR. ENO HYSI**

**Supervisor:** Darren Yuen  
St. Michael's Hospital, ON  
2020-2023: \$27,500

**Project Title:** Quantification of pre-transplantation kidney scarring using photoacoustics

**Category:** Transplantation



**DR. ANN YOUNG**

**Supervisor:** Ron Wald  
St. Michael's Hospital, ON  
2020-2023: \$10,000

**Project Title:** e-Visits for the management of chronic kidney disease

**Category:** Chronic kidney disease

## KRESCENT NEW INVESTIGATOR AWARDS



**DR. JUSTIN CHUN**

University of Calgary, AB  
2020-2023: \$25,000

**Project Title:** Precision medicine in glomerular disease: role for lipid droplets

**Category:** Glomerulonephritis



**DR. THOMAS KITZLER**

McGill University, QC  
2020-2023: \$25,000

**Project Title:** A comprehensive approach to study genetic causes of chronic kidney disease

**Category:** Genetics

\* Includes multi-year funding and projects funded via partnerships