

## **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.



# Message from the **President** and National Executive Director

LOOKING BACK AT 2019, before COVID-19, We pay tribute to the late Dr. Dossetor, an it seems a lifetime ago. The pandemic has brought into sharp focus the important role The Kidney Foundation plays for those impacted by kidney disease. This crisis has simultaneously created an increased demand for help and support of people with kidney disease and an unexpected decrease in revenue to fund these vital services.

This is a stressful time for everyone, as we live and cope with the impact of COVID-19 on all aspects of our lives. We know it is especially stressful for people with kidney disease and those who have a kidney transplant because they are more vulnerable to infection and are at higher risk of serious illness. They need our support now more than ever before. The Kidney Foundation has responded swiftly and effectively to increased requests for programs like short-term financial assistance and has ensured that muchneeded services and information can continue to be delivered virtually.

Our ability to respond in the face of this crisis is, in large part, thanks to the foundational work that was done last year. In 2019, The Kidney Foundation undertook a rebranding exercise to revisit, capture and reflect our commitment, values, and impact on the kidney community. Our new brand, launched at the beginning of 2020, is bold, dynamic, and modern. We have renewed our commitment to patients, their families, and those at risk.

In Canada, one in 10 people is at risk of kidney disease, and it is the 10th most deadly disease. We are bringing kidney disease out of the shadows and into the spotlight, to help Canadians cope with kidney disease, to raise awareness of kidney health and organ donation, to lead research into better treatments and a cure, and to provide impactful programs and supports. In addition to our rebrand, we invested in new and improved tools. Details of our work are highlighted on page 4.

amazing volunteer and lifelong supporter, on page 6. The voices of our patient and family volunteers were invaluable in our advocacy work this year; highlights of some of our efforts from coast to coast can be found on page 8, while a kidney health awareness initiative is highlighted on page 5. We check in on a Kidney Marcher who celebrated a milestone in supporting this unique challenge and fundraiser for the 10 years since its inception; see page 7. And of one our dedicated board members talks about her legacy on page 6.

We are giving voice to issues impacting people with kidney disease, through advocacy efforts to make organ transplantation accessible to those who need it, and to highlight the hidden costs of kidney disease, that are leaving those with kidney disease to bear the financial burden.

Our commitment to serve you better is unwavering.

Together, we will raise the bar on kidney awareness. We will give all Canadians a deeper understanding of the serious life-changing impacts of kidney disease. We will share hope through organ donation awareness, patient impacts and research breakthroughs. We will make a difference through our collective voice advocating for improvements to our health care system and equitable access to treatment. We will search for a cure.

We invite you to renew your equally strong commitment to the kidney community as we raise our voices together to make progress and to make a positive difference.



**GREG ROBBINS** National President





**ELIZABETH MYLES** National Executive Director





# A Fresh Look

## and Renewed Commitment to You

WORK BEING DONE behind the scenes throughout the year in 2019 set the stage to launch into 2020 with a new look and a renewed commitment to kidney health and the support of those impacted by kidney disease.

It is a new era for kidney awareness. We entered 2020 with a new brand, new messages, and new logo – all of which are tuned to best set us up for success in our pursuit of staking our territory as a champion of kidney health and those affected.

The most obvious sign of change, of course, is a new logo and a bold new colour palette – a significant departure from our previous look. Consultations with internal and external stakeholders and audiences were undertaken. Consideration was given to the strength of images and colours in our virtual, website-driven world, while ensuring the Foundation takes centre stage with its presence in print.

The look is disruptive in the most positive sense. The distorted kidney shapes and attention-grabbing modern colours work together to simultaneously disrupt misconceptions surrounding kidney disease. It is designed to encourage the Canadian public to engage in a discussion on kidney health. It's a bold and assertive message that reflects our leadership in kidney health matters.



The logo is not the only thing that is different.

In addition to our rebrand, The Kidney Foundation invested in digital infrastructure, such as our renewed website, which also launched in January 2020. We enhanced online resources and added webinars to our program offerings. We also revamped Kidney Connect, our online peer support community, and enhanced Kidney Community Kitchen, providing recipes and nutritional insights.

Improving our digital capacity and offerings has allowed us to ramp up digital fund-raising channels and to build stronger kidney community networks through a plethora of social and digital platforms which are more accessible and responsive.

# FROGRAMS



189,000

people consulted kidneycommunitykitchen.ca



OVER **2,000** 

people accessed peer-to-peer support through Kidney Connect



454 CAMPERS

supported through \$227,000 in camp subsidies

# **Could You Lose 80% of Something**

## and NOT Know It?

#### A KIDNEY HEALTH MONTH CAMPAIGN WITH A TWIST

THE KIDNEY FOUNDATION'S BC and Yukon Branch joined forces with BC Renal Agency to launch a memorable Kidney Health Month campaign throughout the month of March, called "Could You Lose 80% of Something and NOT Know It?" The campaign used humour to introduce a serious issue and drive home the message that as much as 80% of kidney function can be lost without any obvious symptoms felt.

Aimed at reaching the public, with a focus on high-risk populations for kidney disease, including Chinese, South Asian and Indigenous individuals, the goal was to encourage people to learn more about their kidney health through a simple and quick kidney health self-assessment and to talk to their doctor if they were at risk for kidney disease.

# KIDNEY COMMUNITY STRUTS THE RUNWAY ON WORLD KIDNEY DAY

On March 14 World Kidney Day, a special Fashion Faux-Pas media event was held in downtown Vancouver, building on the campaign theme. Kidney patients, kidney donors and volunteers together with Branch and BC Renal staff, strutted the

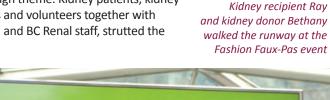


runway, sporting fun and outrageous outfits with a twist. The models were missing key pieces of their outfits to underscore the fact that anyone can lose up to 80% of something without noticing. The highly entertaining and educational event garnered significant media coverage.

"It was so much fun to be part of the fashion faux-pas event with my daughter and to help increase awareness about a seriousness of kidney disease but in such a creative way," says kidney patient and volunteer runway model Ray. "I would do it again in a heartbeat."



- 133,000 video views
- 5,400 completed online assessments
- 900,000 social media advert impressions
- Media coverage on major TV networks, coverage in ethnic TV and print, community media







OVER **3,900** 

people received shortterm financial assistance \$536,000

provided in short-term financial assistance



## The Commitment of a Lifetime

#### A VOLUNTEER'S BOUNDLESS ENGAGEMENT

SYLVIE NEVER PICTURED HERSELF lying on an operating table next to her son. Nevertheless, that's where she found herself a few years ago.

Before then, she had enjoyed a charmed life. She had a great childhood. At the age of 20, she married André, the love of her life; someone whom she boasts could not be "a better, more supportive partner." She even built her own successful business.

Then, one weekend, their 27-year-old son Benoit came home for a visit. He sat Sylvie and André down in the living room, just like they'd done when he was younger, and needed to have a serious chat. He informed them that he hadn't been feeling well and consulted a doctor. His tests revealed that his kidney function was down to 25%. He then announced that his kidney disease will eventually require dialysis or a transplant.

"My immediate thought was, this isn't happening," says Sylvie. "From the outside, Benoit didn't look sick. To look at him, you'd just see a healthy young man. You'd never know that inside, he was dying."

Immediately, Sylvie and André undertook the necessary tests to determine their compatibility to become living kidney donors. Remarkably, it turned out that they were both compatible matches, however, Sylvie's kidney function was slightly better.

So began the lengthy process of additional testing in preparation for an eventual

transplant. During that time, Benoit grew weaker and had a few health scares. Finally, on a December day, Sylvie gave one of her kidneys to her son, and in return, she got her son back.

During her recovery, Sylvie was introduced to The Kidney Foundation. Her involvement started on a smaller scale; volunteering at events and providing pro-bono work for the Quebec Branch. With time, her involvement grew, joining the branch board of directors and eventually becoming its president.

Sylvie's passion for the work done by the Foundation is evident.

"The Kidney Foundation is a marvelous advocate for kidney patients and living donors," she says. "Our family was fortunate in that we could afford for me to take time off work for tests and recovery. But many people aren't in that situation. So that's something we're trying to change, both by raising funds and by advocating with the government."

Determined to continue her contribution to help people affected by kidney disease, Sylvie has chosen to leave a legacy gift to The Kidney Foundation in her will. "I want to fight for this cause as long as I'm alive—and now my fight will continue after I'm gone, too."

"I have an incredible life," Sylvie continues. "I have a wonderful husband, two fantastic children and two adorable grandchildren. I've had an amazing career doing what I love. Leaving a gift in my will is my way of giving back—of saying thank you for the life I've been given."

# TRIBUTE TO OUR CO-FOUNDER DR. JOHN B. DOSSETOR

On Monday, April 6, 2020, Dr. John Beamish Dossetor, co-founder of The Kidney Foundation of Canada, passed away at the age of 94.

Courage, vision, compassion, resilience, ingenuity, determination, and action describe Dr. Dossetor. His commitment to patients and kidney health remains central to The Kidney Foundation, its mission, and vision.

Born in Bangalore, India, in 1925, Dr. Dossetor received his medical training at Oxford University in London, England. In 1955, he emigrated to Canada to work as a teaching fellow and medical resident at McGill University in Montreal, and three years later, he coordinated the first kidney transplant in the British Commonwealth.

Over 55 years ago, Dr. Dossetor worked with several Montreal businessmen, led by the Tarder family, to create a new organization that would focus on kidney research, so that kidney failure would not mean certain death. That was the beginning of The Kidney

Foundation of Canada.

"Dr. Dossetor was a true pioneer in the field of kidney health, organ donation, medical ethics, and transplantation," said Kidney Foundation

National President Greg Robbins. "His decades of groundbreaking work made it possible to save the lives of so many in our kidney and transplant community. He will always hold a place of honour at The Kidney Foundation as our beloved co-founder."

In 1970, he was appointed Director of the Division of Nephrology and Immunology at the University of Alberta and Co-director of the Research Transplantation Group with Dr. Erwin Diener. Between 1986 and 1996, he was Director of Bioethics at the University of Alberta and Vice-Chair of the Provincial Health Ethics Network in Alberta. He founded what is now the John Dossetor Health Ethics Centre. In 1995 he was named an Officer of the Order of Canada.

"In the name of everyone who is affected by kidney disease, we extend our deep gratitude and appreciation for his remarkable contributions to our country," said Elizabeth Myles, National Executive Director of The Kidney Foundation. "His was a life well lived."

# **Celebrating 10 Years**of Kidney March

NEARING THE FINISH LINE of Alberta's 2019 Kidney March, Heather felt a rush of emotion. She was on the cusp of finishing her 10<sup>th</sup> gruelling hike through the foothills of the Rocky Mountains. The Calgary-based dialysis nurse teared up as she saw a group of volunteers and other marchers cheering her on at the top of the final hill. At that point, Heather and her best friend, nurse Janice, realized just how far they had walked over the years.

"We are really going to do this," Heather thought at the time. "We are going to walk a thousand kilometres, and we have literally walked every step of the way."

Heather has been a part of the Kidney March from its very beginning. She was among the first participants to sign up



for The Kidney Foundation's fundraising event – the only one of its kind in the world. As a nurse working with renal patients, she came to understand the challenges of the disease and just how many Canadians are affected by it.

"Kidney patients inspire me everyday. I cannot walk in their shoes, but I can show my support by walking beside them and supporting them," Heather says. "I believe there will be a cure for kidney disease, and by raising much-needed funds we can help make that happen."

Heather admits she was a bit nervous as she began her first trek though Kananaskis Country to Calgary in 2010. Even as a practised camper and runner, she wasn't sure how it would go. That first march was full of incredible memories, but also a few tough moments.

"The camp was completely different from what it is today. The weather was very cold. Some marchers put wet towels from showers on their tents to dry overnight, and when they woke up the towels were frozen."

Over the years, the Kidney March has grown and evolved to become an annual tradition for a diverse group of people. Doctors, nurses, kidney patients and their families come together to walk and share stories. At the end of the day, for those with energy to spare, there is karaoke and dancing. A record 600 participants took part in the 2019 event. On its landmark 10th anniversary, organizers surpassed their goal and raised more than 1.4 million dollars.

"It is a family, it is a community, it is people working together for a common goal," Heather says. "I know it will be life-changing for anyone who steps forward. It doesn't matter if you finish it, it is about the journey."

- ARTICLE BY HEIDI WESTFIELD



Ten-time Kidney March participants Heather and Janice.







# **Organ Donation Advocacy**Takes Big Step Forward

KIDNEY FOUNDATION VOLUNTEERS
AND STAFF are leading the charge in keeping patient voices centric in opportunities to influence system changes and improvements in kidney care. One such opportunity which saw lot of forward movement related to organ donation in 2019 was the collaboration happening through the Organ Donation Transplant Collaborative (ODTC).

"The past year, advocacy activity has been particularly significant in the organ donation portfolio," said Lydia Lauder, National Director of Program and Public Policy. "Our volunteers and some staff are integral members of the ODTC through several channels."

The ODTC is led by Health Canada, and includes of all those involved in the organ donation and transplantation system across Canada: Canadian Blood Services, provincial and territorial ministries of health, organ donation organizations, federal agencies, and the Canadian Donation and Transplantation Research Program. The ODTC is addressing numerous priorities, such as maximizing donor identification in hospitals, increasing living donations, and improving system efficiency and effectiveness, with the goal of improving transplant outcomes.

As part of the ODTC, and in partnership with patients, the Foundation played a key part in ensuring that the voice of people... organ donors and recipients, patients and family members, was also represented at the ODTC. The Kidney Foundation was instrumental in establishing the Patient Awareness and Advocacy Committee (PAAC). "We are bringing together patients and advocates together, and endeavouring to include a patient advocate in every ODTC working group to ensure their voices are represented across all areas of the collaborative," said Ms. Lauder.



Several Kidney Foundation of Canada representatives joined The Honourable Randy Delorey, Minister of Health and Wellness for the Province of Nova Scotia, in celebration of the proclamation of World Kidney Day on March 14, 2019. From left are Kidney Foundation Development Officer Michelle MacMullin; volunteer Carol Singer; Minister Delorey; volunteer Hazel Muise; volunteer Cydney Kane, and Development Manager Ed Saunders.

Each PAAC member participates in other subcommittees. The PAAC is then able to come together to identify key opportunities for additional input and share idea generation with each of the other working groups, creating a cycle of continuous knowledge exchange with the patient and family voices.

"This work is very exciting, informative and emotional," said PAAC member Randy Spensley, kidney transplant recipient. "It is great to be able to carry on our strong messages of understanding and, most of all, hope. PAAC to me is so much more than a committee, it is a family made up of like-minded people from coast to coast. We may be small, but we are influential."

PROVINCIAL ADVOCACY
HIGHLIGHTS

"Providing patients and living donors an equal voice at the table with medical professionals and policy makers is essential," said Elizabeth Myles, Kidney Foundation National Executive Director. "Through PAAC, patient advocates have been empowered to make real change happen within the system so that the patient experience is at the forefront of decision making in regard to organ donation in Canada."



# **Six Degree Challenge**Casts a Wide Net

IN THE GROWING WORLD of digital connections, it is easy to find links in common with those within a community or a province for that matter. The Kidney Foundation found out just how connected people were to kidney disease through a unique awareness and fundraising initiative: Six Degrees of Kidney Disease campaign.

The #SixDegreeChallenge online campaign invigorated a conversation on the connection so many Canadians have to kidney disease. With one in ten Canadians living with kidney disease, every person in the country knows someone living with this often invisible disease - a disease with no cure.

In an effort to highlight these connections, the #SixDegreeChallenge campaign encouraged Ontario residents to share a picture of themselves throwing "The Six" (holding up six fingers), captioning it with their own story and connection to kidney disease.

The #SixDegreeChallenge campaign was championed by Kidney Foundation key partners:
Canadian musical icon Tom Wilson and 2014's Miss Intercontinental
Canada Delaney Holley. Two
Canadians who had never met and yet were connected by the disease through their own personal backgrounds. It rallied the community and reached people who may have not been aware of kidney disease previously.

"Often times kidney disease is an invisible disease, and so this Six Degree Challenge sheds light on the fact that we're all connected by this," said Ms. Holley. "I'm glad I could be part of such an innovative and fun social campaign to get the word out."

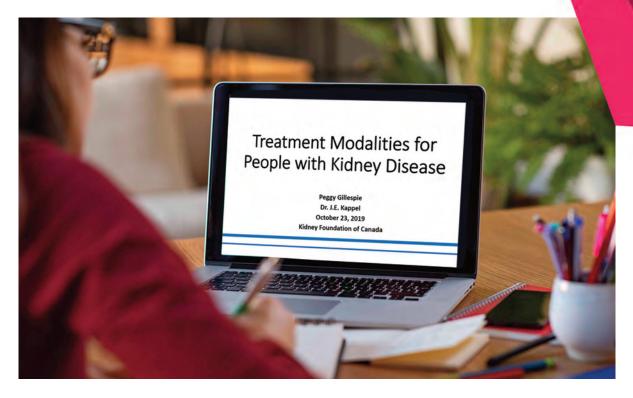
In addition to Wilson and Holley, stories of connections were shared throughout the campaign by other notable Canadians, including Bif Naked, Cristina Howorun, Kathleen Wynne, Roger Petersen, The Tenors and Teri Hart. In all, over two million people were reached by the campaign through 26,000 engagements in social media posts.

The two-week high energy campaign culminated with a 24-hour giving day late in March, which is Kidney Health Month. Over \$31,000 was raised for research and



## **Interactive Webinars**

## **Provide Valuable Connections**



THE KIDNEY FOUNDATION OF CANADA is tapping into new technologies to broaden the reach of its support and educational services. The Foundation produced a series of six interactive webinars in 2019. The topics ranged from live donor transplants to patient advocacy and mental health. Four of the online sessions were hosted in English, and two in French.

"I think the value of webinars is that we can be proactive and connect with people across Canada who really feel like they need information and more connections," notes Lydia Lauder, The Kidney Foundation's National Director of Programs and Public Policy. "We can provide support for patients and caregivers who may not otherwise be able to access it as readily."

The Foundation launched its first webinar series in 2017. Since then, hundreds of people across the country have logged on to the presentations from their home computer or connected by phone. About half of the participants are patients, and the other half family, caregivers, doctors and healthcare workers.

The webinars usually feature two speakers: an expert in the subject area, and a patient perspective. People taking part can send in questions prior to a webinar by email, or use chat boxes to have their questions answered in real time.

Peggy, of Nova Scotia, has lived with renal failure for decades. She was a presenter in one of the 2019 web sessions, and found it to be a positive experience.

"Webinars are a very important way of keeping all patients informed and up-to-date on what is happening In regards to their care and health," she says.

Feedback has been overwhelmingly positive. A recent survey found than 82 per cent of participants agreed, or strongly agreed that the advice from the webinar they attended was useful. The same survey percentage found the speakers were professional, and that it was worth their time.

"To be effective, education needs to be delivered in multiple ways and webinars should be in our toolbox," says Dr. Joanne Kappel, a webinar presenter, and nephrologist based in Saskatchewan.

Ms. Lauder believes online video seminars will continue to play a valuable role in the years to come. They provide information to patients that may not be immediately available from their healthcare team. Plans are underway to create new sessions that will be interactive, practical and even more relevant than they have been in the past.

- ARTICLE BY HEIDI WESTFIELD

# KIDNEY FOUNDATION EDUCATIONAL MATERIALS



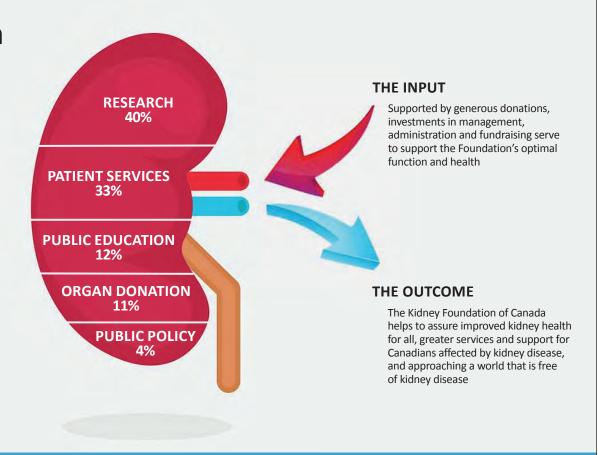
21,000
Patient Handbooks distributed



**70,000**Educational Brochures distributed

# **Spending**

By Program



**Total Social Media Followers** 

(All Platforms) 64,000









**Newsletter Subscribers** (Print & Electronic) **88,000** 



Website Users 701,000





#### 2019-2020 NATIONAL BOARD OF DIRECTORS

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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







# **Creating a Canadian Platform**

# to Accelerate Research for Glomerulonephritis Treatment

DR. HEATHER REICH is a clinician-scientist at Toronto's University Health Network, and an Associate Professor at the University of Toronto where she holds the Gabor Zellerman Chair in Nephrology Research. The Toronto-based nephrologist is working to find new ways to detect and treat glomerulonephritis (GN), one of the leading causes of kidney failure in Canada. Glomerulonephritis means inflammation and scarring of the filters of the kidney, and it is caused by several conditions including Focal Segmental Glomerulosclerosis (FSGS), IgA Nephropathy (IgAN), Membranous Nephropathy (MGN), and others.

> THE GOAL IS TO DEVELOP **MEDICATIONS WITH** FEWER SIDE EFFECTS THAT **ARE MORE EFFECTIVE** FOR THAT INDIVIDUAL PATIENT'S DISEASE.

"When I was a trainee earlier in my career, I became focused on GN because it was an opportunity to actually prevent kidney failure," she recalls. "It is catching patients before they have end-stage disease and their only option is dialysis or a transplant. I am very passionate about preventing kidney failure."

While GN diseases are relatively rare in Canada, they can have a devastating impact on patients and their families. If the conditions are caught early, there is a better chance of limiting kidney damage, though the side effects of treatment can be as bad as the disease itself. Because there is no specific treatment approved for GN, patients often receive high doses of immune lowering medications called corticosteroids (prednisone). This does not cure GN, and produces very difficult side effects that may be more difficult on the body than the disease itself.

Dr. Reich, in cooperation with other nephrologists across the country, has launched a national program to look for new solutions for GN patients to help understand the individual patient experience with GN. The Canadian Glomerulonephritis Registry (CGNR) is a web-based network operating across the country from British Columbia to the Atlantic provinces. It was set up to support innovative discoveries and generate better treatments for GN diseases.

"We have created a platform for scientists to participate in translational research," Dr. Reich says, noting the registry is collecting bio-samples of DNA, urine and blood to better understand how GN diseases In her more than 15 years as a nephrologist, develop. Researchers plan to recruit GN patients across the country to be part of a new medical cohort. Individuals enrolled in the study will be seen every six months for blood tests and health updates.

With a larger database of patients, scientists will have a deeper pool of information to work with. They can look for specific genes and proteins that provide important clues to help predict how a disease will progress. "Our goal is to make GN research more accessible to patients and to doctors and scientists in centres across Canada," says Dr. Reich. "As we grow, my goal for the future is for this resource to also be a hub for patients to access information about their condition and be able to learn about clinical trials of new treatments."

In recent years, Dr. Reich has seen an explosion of interest from the pharmaceutical industry in developing targeted treatments for diseases like GN. There are, she observes, an unprecedented number

of clinical trials underway testing new medications that are personalized and less toxic. For example, scientists are looking for alternatives to steroids, which are often used to treat the inflammation associated with GN conditions. "The steroids work but they are kind of a sledgehammer used for many diseases, and they don't work in all patients. The goal is to develop medications with fewer side effects that are more effective for that individual patient's disease."

Companies may not always think of Canada for trials because of our smaller population. Having a central resource for GN helps bring patients and their doctors together to bring trials to Canada. Centres relatively new to research can also lean on other members of the GN community for support to begin to offer access to research studies across Canada.

Dr. Reich has seen first-hand the difficulties that come with a GN diagnosis. She is encouraged by the wave of interest and discoveries, and believes that new treatment options are on the horizon. The key now is recruiting more GN patients to be partners in the research process, and to maintain the support needed to sustain this endeavour.

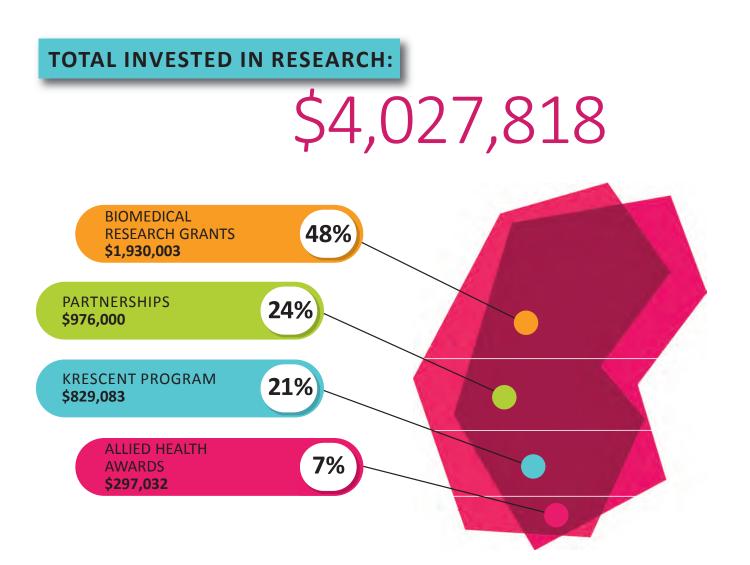
"It is a very exciting growth period in the GN world. I have been a nephrologist since 2002 and never have I seen so many upcoming clinical trials in GN. There is a tremendous interest in developing new medications. I am deeply grateful to The Kidney Foundation for support throughout my career, and I hope that building this community allows me to 'give back' and help boost GN research capacity in Canada."

- ARTICLE BY HEIDI WESTFIELD



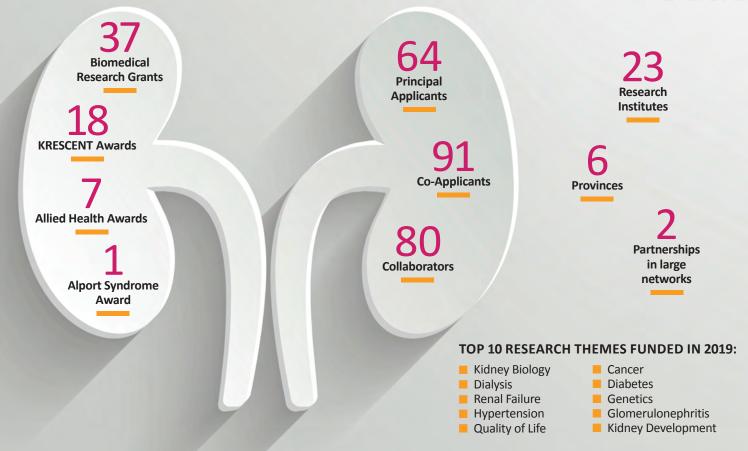
# **Research** by the Numbers

RESEARCH CONTINUES TO BE a central pillar of The Kidney Foundation's mission. In 2019, the Foundation provided over \$4 million to support Canadian kidney researchers, which represents 40% of our mission-focused budget. Over the last 55 years, the Foundation invested over \$124 million in grants and awards to find better treatments and improve the care and quality of life for patients living with kidney disease. Translating new findings into positive impacts for patients requires significant research effort and sustained funding.



### In 2019, The Kidney Foundation provided funding to:





#### **NEW RESEARCH FRAMEWORK 2019-2024**

As a follow up to the HORIZONS 2022 work-shop, a committee comprising 12 members of the kidney community including patient partners, basic and clinical scientists worked together in 2019 to develop a strategic research framework to best advance The Kidney Foundation's mission to fund and stimulate innovative research for better treatments and a cure for kidney disease.

While the committee recommended that the Foundation continue funding research through the current suite of programs (The Biomedical Research

Grant competition, the KRESCENT competition and the Allied Health Competition), the following research priority areas were identified:

- Stakeholder-identified priorities
  (patient-oriented research) to improve
  outcomes grouped under five themes:
  Communication & Connectivity,
  Health System Approaches, Promoting
  Health & Quality of Life, Keeping
  your Kidneys Healthy, and Treatment
  of Kidney Disease
- Innovative research for transformational change

Population health research to build the evidence base to demonstrate seriousness of kidney disease and public health impact

The strategic research priorities will be used to inform research funding, and to create "priority announcements" with dedicated funding towards one of these strategic research areas and assess future partnership opportunities.

To read the full report, please consult the website: kidney.ca/research/the-impact-of-research/reports

#### **2019 HIGHLIGHTS: RESEARCH COMPETITIONS**

Advancing kidney research remains among the Foundation's top priorities. In 2019, the maximum amount for operating grants was increased by 20%, bringing the total to \$120,000, for both the Kidney Health Research Grant and the Allied Health Kidney Research Grant competitions, effective in 2020.

The Foundation also changed the name of its largest research competition formerly known as Biomedical Research Grant to Kidney Health Research Grant to emphasize that the research funding supports the four research pillars (biomedical, clinical, health systems, & population health) and to accurately describe the funded research.

All research competitions have now transitioned to a new online grant application and review system in 2019 creating efficiencies and streamlining the process for applicants and reviewers.





# 2019: **New Funded** Researchers by Program

#### **BIOMEDICAL RESEARCH GRANTS**



DR. TODD ALEXANDER University of Alberta, AB 2019-2021: \$100,000 Project Title: Phosphate added to food moves between intestinal cells and is therefore more readily absorbed Category: Renal Failure





DR. RAHUL CHANCHLANI Co-applicants: Michael Zappitelli, Ron Wald, Danielle Nash, Eric McArthur, Rulan Parekh, Lehana Thabane McMaster University, ON 2019-2021: \$99,849 Project Title: Long-term outcomes after acute kidney injury among neonates and children in Ontario: A population-based cohort study Category: Renal Failure



DR. JEFFREY DICKHOUT McMaster University, ON 2019-2021: \$100,000 **Project Title: Preventing** kidney disease by preventing protein misfolding Category: Kidney Biology



DR. AMIT GARG Co-applicants: PJ Devereaux, Maura Marcucci, Pavel Roshanov, Raja Jayaram, Jessica Sontrop, Meaghan Cuerden Knight, Michael McGillion Lawson Health Research Institute, ON 2019-2021: \$100,000 Project Title: Does a strategy to avoid low blood pressure during surgery protects the kidnevs? Category: Renal Failure



DR. RICHARD HÉBERT University of Ottawa, ON 2019-2021: \$100,000 Project Title: The role of prostaglandin E2 and their receptor subtypes in kidney disease Category: Hypertension



DR. NINA JONES University of Guelph, ON 2019-2021: \$100,000 Project Title: Hold on tight! A molecular approach to understand podocyte adhesion

Category: Kidney Biology



DR. ANDRAS KAPUS Co-applicant: Casimiro Gerarduzzi St. Michael's Hospital, ON 2019-2021: \$100.000 Project Title: The role of injured kidney tubules in chronic kidney scarring Category: Kidney Biology



DR. ANDREW KARAPLIS Co-applicants: Mark Lipman, Dibeyendu Panda Jewish General Hospital, QC 2019-2021: \$100,000 **Project Title:** Preventing polycystic kidney disease Category: Renal Failure



DR. ANDREW **MAKRIGIANNIS** Dalhousie University, NS 2019-2021: \$100,000 Project Title: Regulation of immune function in the kidney Category: Kidney Biology



DR. ISTVAN MUCSI Co-applicants: Marta Novak, Geoffrey Liu, Doris Howell, Madeline Li, Gihad Nesrallah, Nicholas Mitsakakis. Tran Truong University Health Network, ON 2019-2021: \$99,670 Project Title: A study of patient-reported distress measures Category: Quality of Life



DR. DANIEL MURUVE University of Calgary, AB 2019-2021: \$100,000 Project Title: How the immune system of the kidney contributes to disease Category: Kidney Biology



DR. FRANCES PLANE Co-applicant: William Cupples University of Alberta, AB 2019-2021: \$100,000 Project Title: How blood flow to different parts of the kidney is coordinated Category: Kidney Biology



DR. PIETRO RAVANI Co-applicants: Kathryn King-Shier, Meghan Elliott, Hiremath Swapnil, Braden Manns, Brenda Hemmelgarn, Matthew Oliver, Nairne Scott-Douglas, Robert Quinn, Matthew James, Jennifer MacRae University of Calgary, AB 2019-2021: \$100,000 **Project Title:** Individualizing the method of connecting people with kidney failure to the hemodialysis machine Category: Dialysis



DR. DARREN RICHARD Co-applicant: Richard Larivière Université Laval, QC 2019-2021: \$100,000 Project Title: Roxadustat. a drug to treat anemia in chronic kidney disease, may cause arterial calcification Category: Renal Failure



DR. KATALIN SZASZI
St. Michael's Hospital, ON
2019-2021: \$100,000
Project Title: Claudin-2 in
kidney disease
Category: Kidney Biology



■ DR. TOMOKO TAKANO
Co-applicants: Ciro Piccirillo,
Susan Samuel
Research Institute McGill
University Health Centre, QC
2019-2021: \$100,000
Project Title: How can we
treat children with nephrotic
syndrome without using
steroids?

Category: Glomerulonephritis



■ DR. BRAD URQUHART
Co-applicants: Andrew House,
Matthew Weir, Guido Filler,
Michael Knauer
The University of Western
Ontario, ON
2019-2021: \$100,000
Project Title: Finding better
ways to detect and monitor
kidney disease
Category: Predictive
Biomarkers



DR. MICHELE ZAPPITELLI
Co-applicants: Paul Nathan,
Tal Schechter-Finkelstein,
Jason Pole, Lillian Sung,
Eric McArthur, Danielle Nash,
Abhijat Kitchlu, Asaf Lebel,
Rahul Chanchlani
The Hospital for
Sick Children, ON
2019-2021: \$100,000
Project Title: Long-term
kidney and blood pressure
problems in children treated

**ALLIED HEALTH RESEARCH GRANTS** 

for cancer Category: Cancer



DR. SHAO-LING ZHANG
Centre de recherche CHUM,
QC
2019-2021: \$100,000
Project Title: Hedgehog
interacting protein
expression in diabetic
kidney disease
Category: Diabetes

#### ALLIED HEALTH DOCTORAL FELLOWSHIPS



MS. ARRTI ANIL BHASIN Supervisor: Michael Walsh McMaster University, ON 2019-2021: \$50,000 Project Title: The epidemiology of depression and anxiety in patients with chronic kidney disease Category: Quality of Life



Supervisor: Martine Puts
University of Toronto, ON
2019-2021: \$58,000
Project Title: Predicting patient
participation and their outcomes
during end-stage kidney disease
treatment decisions
Category: Quality of Life



DR. MARY SMITH
Co-applicants: Vanessa Silva
e Silva, Kara Schick-Makaroff
Queen's University, ON
2019-2021: \$97,710
Project Title: Circles towards
indigenous solutions for
kidney health: a strengthbased approach
Category: Quality of Life



Co-applicant: Ted Lakowski
University of Manitoba, MB
2019-2021: \$99,892
Project Title: Optimizing
antibiotic dosing for patients
on hemodialysis: a high-risk
population
Category: Dialysis

# ALLIED HEALTH SCHOLARSHIP



MS. RANI FEDORUK Supervisor: Diana Mager University of Alberta, AB 2019: \$5,000 Project Title: Frailty and the elderly in chronic kidney disease Category: Quality of Life

# SPECIAL RESEARCH PROJECT GRANT PREDICTIVE BIOMARKERS



DR. ANA KONVALINKA
Co-applicant: Igor Jurisica
University Health Network, ON
2019-2023: \$450,000
Project Title: Urine markers of
kidney transplant scarring
Category: Predictive Biomarkers

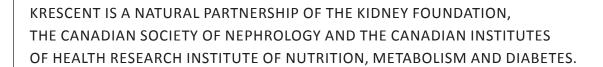
#### **CDTRP PARTNERSHIP INNOVATION GRANTS**



DR. MARIE-CHANTAL FORTIN
Co-applicant: Tania Janaudis-Ferreira
Centre de recherche CHUM, QC
2019-2020: \$30,000
Project Title: Acceptability and
feasibility of the Kidney Transplant
Physical Activity and Social Club
(KEEP ACTIVE Club)
Category: Transplantation



■ DR. BETHANY FOSTER
Research Institute McGill
University Health Centre, QC
2019-2020: \$30,000
Project Title: Associations
between Sex Hormone
Levels and Immune Profiles
among Kidney Transplant
Recipients
Category: Transplantation





#### **KRESCENT NEW INVESTIGATOR AWARDS**



DR. MEGHAN ELLIOTT University of Calgary, AB 2019-2022: \$225,000 + \$25,000 infrastructure support **Project Title:** Supporting Engagement in Chronic Kidney Disease Care and Research Category: Chronic Kidney Disease



DR. GREGORY

**HUNDEMER** 

Ottawa Hospital Research Institute, ON 2019-2022: \$210,000 + \$25.000 infrastructure support **Project Title:** Characterizing Renal Outcomes in Overt and **Subclinical Aldosterone Excess** 

Category: Hypertension



DR. MATTHEW LANKTREE McMaster University, ON 2019-2022: \$210,000 + \$25,000 infrastructure support Project Title: Assessing the Omnigenic Contribution to Chronic Kidney Disease Category: Genetics

#### **KRESCENT PARTNERSHIP** WITH CIHR IHDCYH **NEW INVESTIGATOR GRANT**



DR. MATHIEU LEMAIRE The Hospital for Sick Children, ON 2019-2022: \$105,000 **Project Title:** Studying why abnormal fats in blood vessel leads to blood clots in the kidneys of children with a rare genetic disease Category: Genetics

#### **KRESCENT POST-DOCTORAL FELLOWSHIPS**



DR. SERGI CLOTET **FREIXAS** Supervisor: Ana Konvalinka University Health Network, ON University of Calgary, AB 2019-2022: \$165,000 Project Title: Sex and Human Kidney Metabolism: New Insights into Diabetic Kidney Disease Category: Diabetes



DR. JANINE FARRAGHER **Supervisor:** Brenda Hemmelgarn 2019-2021: CIHR Award Project Title: A Pilot RCT of the PEP Program for Adults on Chronic Dialysis with Fatigue Category: Quality of Life



DR. TYRONE HARRISON Supervisor: Brenda Hemmelgarn University of Calgary, AB 2019-2022: \$130,000 Project Title: Improving the perioperative care of patients with end-stage renal disease Category: Dialysis

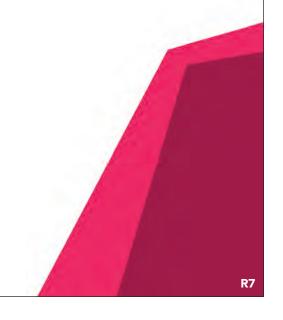


DR. CLAIRE MARTIN Supervisor: Anne-Claude Gingras Mount Sinai Hospital, ON 2019-2022: \$12,000 + CIHR Award Project Title: Proteomic mapping of the kidney's blood filtration barrier

Category: Kidney Biology



DR. MARKO SKRTIC **Supervisor:** Lisa Robinson University Health Network, ON 2019-2022: \$195,000 Project Title: Pro-resolving mediators and Slit2-Robo pathway in acute kidney injury Category: Acute Kidney Injury





#### DR. RICHARD GILBERT

# New Treatment for Diabetic Kidney Disease

Despite all our currently available treatments, diabetes remains the most common cause of endstage kidney failure in Canada, which requires dialysis or transplantation to preserve life. Stem cells offer the exciting potential of not only slowing the progression of diabetic kidney disease but also of reversing the disease once it has occurred. While highly successful in animal studies of heart disease, human stem cell studies have been far less impressive. Among the likely reasons for this is the type of cells that are used in humans, as opposed to those used in animals.

Notably, donor stem cells in animal studies are derived from healthy animals with the same genetic makeup. To avoid rejection, human studies have focused on using cells derived from the patient himself. As these stem cells come from an "unhealthy" individual, they do not function as well. Dr. Gilbert's study seeks to find a way around this key obstacle.



His research team has found that many types of stem cells work, not by creating new tissues but by secreting factors that allow organs to repair themselves. After several years of painstaking research, they have identified the factor that they believe is responsible for the kidney-protective properties of certain stem cells. The project objective was to test this factor, called CXCL-10, to see whether its administration can stop the development of diabetic kidney disease in a mouse model. Their findings confirmed this

hypothesis and showed that CXCL-10 treatment prevented kidney scarring and the development of diabetic kidney disease in the animals. This work was published in the American Journal of Pathology.

#### WHAT THIS MEANS FOR PATIENTS:

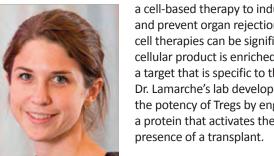
If CXCL-10 proves to be successful in future human trials, this new treatment alternative could help prevent or stop the development of kidney disease in diabetic patients.

#### DR. CAROLINE LAMARCHE

# Harnessing the Immune System to Decrease Kidney Rejection

Transplantation is the best and sometimes only treatment for end-stage kidney failure. Immunosuppressive drugs make transplantation possible, but since these drugs do not only suppress the cells reactive to the transplanted organ but also the entire immune system, they come at the price of an increased risk of infection and cancer. The drugs are not perfect; many kidneys are still lost to rejection.

The goal of Dr. Lamarche's research is to improve the success of transplantation, by finding ways to re-educate the recipient's immune system to tolerate the transplanted organ. Her strategy is to harness the natural immunosuppressive properties of a type of white blood cell called T regulatory cells (Tregs). Tregs naturally regulate immune responses by ensuring the immune system attacks infectious or harmful substances without over-reacting to self or to non-harmful foreign proteins. Research has shown that Tregs could be used as



a cell-based therapy to induce immune tolerance and prevent organ rejection. The efficacy of Treg cell therapies can be significantly enhanced if the cellular product is enriched for Tregs that recognize a target that is specific to the transplanted organ. Dr. Lamarche's lab developed a method to improve the potency of Tregs by engineering them to express a protein that activates them when they are in the

This technology has now been patented and through a collaboration with the industry, a first-in-man clinical trial should start in the following years. Dr. Lamarche's team has demonstrated that this technology might be useful to prevent acute rejection but not so much to treat it if already established.

#### WHAT THIS MEANS FOR PATIENTS:

Dr. Lamarche is hopeful that this new technology will allow the development of personalized cell therapy treatment to harness the patient immune system and prevent graft rejection.



#### DR. GEORGE YOUSEF

# Predicting the Effectiveness of Kidney Cancer Treatment

Kidney cancer is an aggressive disease and when the tumor spreads outside the kidney (called metastatic disease), the treatment becomes very difficult and patient survival drops significantly. Although the introduction of sunitinib treatment (a drug used to treat kidney cancer) has improved patient outcomes, most patients will eventually develop resistance to the drug. Currently, there is no way for physicians to predict which patients will respond well to sunitinib.

Dr. Yousef has been studying the changes in small molecules (called microRNAs) between kidney cancer patients who benefited from sunitinib treatment and those who did not.



His study has shown that some microRNAs can predict the effectiveness of treatments in kidney cancer. It demonstrated that microRNA levels are altered with sunitinib response and that certain microRNAs are changed after treatment. MicroRNAs were also associated with short term and long-term survival and they played a role in the molecular pathways that contribute to kidney cancer progression.

#### WHAT THIS MEANS FOR PATIENTS:

This is a very important issue since predicting response to treatment can help physicians to determine which patients will benefit from this treatment and those that should have a different treatment. It will help patients avoid complications and side effects of the drug if clinicians know that they are not going to benefit.

# Deprescribing in Patients on Hemodialysis

Polypharmacy (concurrent use of multiple medications by a patient) has been associated with an increased risk of non-adherence to medication regimens, adverse drug events, falls, hospital admissions and mortality. Patients with end-stage renal disease on hemodialysis (HD) are exposed to polypharmacy by taking on average 12 medications per day. Deprescribing tools have been developed to reduce polypharmacy and have been successful in the elderly population, but these tools have not been applied directly to the chronic kidney disease (CKD)

population. Furthermore, many medications currently used in HD patients lack the high-quality evidence for efficacy and safety seen in the general population and the role of these medications in HD patients is often not known. The aim of the project was to develop tools (algorithms) to guide the re-assessment and deprescribing of specific medications that lack evidence for efficacy and safety in HD patients and to determine the effectiveness of these tools in reducing polypharmacy.

Dr. Battistella and her team developed a representative set of medication-specific deprescribing algorithms validated by nephrology experts for nine identified medications that are often inappropriately prescribed. To reach this goal, a total of 45 Canadian nephrology experts were interviewed. These algorithms will feed into a national deprescribing study that aims to tackle the issue of polypharmacy in Canadian patients



on HD, ultimately increasing patient safety and wellbeing by reducing or mitigating the risks of drug side effects and unwanted interactions between drugs.

The algorithms were presented at the American Society of Kidney Disease Annual Meeting in November 2019. The study group involves members within the Can-SOLVE CKD Network / Knowledge Translation Community of Practice and our results will be disseminated to network stakeholders, funding partners, patients, and the general public.

Through the validation process, positive feedback has already been garnered from over 70 Canadian clinicians, many of which have requested copies of these completed toolkits for use in practice. Dr. Battistella is currently working on a publication and Canadian clinicians will be able to access these toolkits on an upcoming webpage to encourage dissemination and implementation. Three pharmacy research students also worked on patient information pamphlets and videos.

#### WHAT THIS MEANS FOR PATIENTS:

This initiative will be the basis for the development of national consensus driven medication deprescribing algorithms that will be implemented in clinical practice for hemodialysis units across Canada.





#### DR. MOUMITA BARUA

# Genetic Research Helps Unlock Mysteries of a Rare Kidney Disease

DR. MOUMITA BARUA is working to improve clinical outcomes, and the quality of life for people diagnosed with genetic kidney diseases. She is a graduate of the KRESCENT Post-Doctoral Fellowship (2010-2013) and New Investigator (2016-2019) programs. Dr. Barua is now a clinician-scientist with Ontario's University Health Network and an Assistant Professor at the University of Toronto's Department of Medicine. In both her research and clinical practice, she is focused on learning more about how these disorders develop, and why certain individuals armore vulnerable to kidney disease.

"I have always been the type of person who wants to know 'why'. Why does someone get a kidney disease and other people don't? When I was going through my training, I sometimes found the answers a bit unsatisfying," Dr. Barua says. "That drew me to research, to find more answers and think about things in a different way."

Her research has centered on a kidney disorder called Focal and Segmental Glomerulosclerosis (FSGS). The disease is characterized by damage to the kidney filters, which leads to protein in the urine, kidney damage and in some cases kidney failure. FSGS has a number of causes – some genetic and others the result of an underlying illness or infection. Dr. Barua is seeking ways to better identify the cause of FSGS in individual patients, so doctors can provide more personalized treatments and care.

"The starting point is to understand what you are dealing with. [You] cannot come up with really effective therapies if you don't understand what is going on," she explains. "I really think that genetics is a huge part of that. We want to use the unique biologic signature of a patient to tailor medication and choose the appropriate therapy for that person."

Finding new treatments is especially beneficial for Canadians diagnosed with FSGS. While doctors can identify the disorder with a biopsy, there is no medical tool to pinpoint its exact cause. Most Canadians diagnosed with FSGS are prescribed steroids, which have a lot of toxicity and unwanted side effects. While steroids often work in cases where scarring is the result of inflammation, they are not usually as effective when the underlying cause is genetic. Steroids, Dr. Barua observes, only work in about half of patients with FSGS.

Recent advances in DNA analysis and genome sequencing are helping researchers better identify the causes of FSGS. Dr. Barua's lab has discovered that about five per cent of adults with FSGS have a genetic mutation in type 4 collagen, also known as Alport Syndrome. Her lab's findings are being replicated in other international studies.

"Collagen is something that provides structure to all of our organs including the kidney," she explains, noting most Canadians are only aware of the collagen used to maintain a youthful appearance. "Type 4 collagen provides important structure to the kidney filters. When there is a mutation, it leads to a weakening of the filters and kidney damage."

With this new discovery, nephrologists can now look for type 4 collagen mutations in patients and, when found, choose to forego steroid treatments in those individuals. Dr. Barua stresses more is being done than simply removing an ineffective therapy. There are also two new medications being tested for people with type 4 collagen disorders (https://alportsyndrome.org/research). These, and other advancements, point to a better treatment landscape for Canadians living with FSGS and other kidney diseases in the years ahead.

"We have come a long way in the past few years because of a lot of advances in science and technology related to genetics, gene editing and stem cell science," she says. As a clinician-scientist, Dr. Barua has an opportunity to drive these new advances and provide better solutions for patients. "Being a researcher is an amazing job path because there is so much reward in it. There is a lot of failure too, and you have to be okay with that. But those successes, even if they are really rare, are rewarding."



– ARTICLE BY HEIDI WESTFIELD

#### **DR. BRENDAN BARRETT**



# Medal for Research Excellence Recipient 2019

FOR OVER 25 YEARS, Dr. Brendan Barrett has contributed generously to the Canadian kidney research landscape through his work in transformational research. He is currently the Chief Scientific Officer of the Translational and Personalized Medicine Initiative, funded by the Canadian Institute for Health Research (NL SUPPORT, Strategy for Patient-Oriented Research), the province of Newfoundland & Labrador, the Atlantic Canada Opportunities Agency and IBM.

Dr. Barrett was presented the prestigious Medal for Research Excellence at a reception held in his honour on September 17 at The Frank and Eileen Gronich Lecture Theatre, Memorial University in St. John's, Newfoundland.

"Dr. Barrett is a consummate ambas-sador of the best Canadian kidney investigation has to offer on the world stage," says Elizabeth Myles, National Executive Director of The Kidney Foundation of Canada. "He serves as a valuable mentor and role model to his junior colleagues thanks to his leadership, advice and team building prowess."

Described by his colleagues as a "gentle giant" and a "pillar" of Canadian research,
Dr. Barrett is also the principal investigator for eastern Canada for the Strategy for Patient-Oriented Research (SPOR) Chronic Kidney Disease network under review by CIHR and co-investigator on the CIHR funded ACCESS trial investigating the role of fistulas versus other access for elderly patients starting dialysis.

Dr. Barrett has been an influential, intelligent and sensible leader in several important Canadian studies, including CanPREVENT: the Canadian Prevention of Renal and Cardiovascular Endpoints Trial which enhanced understanding of how to improve multidisciplinary care for people with chronic kidney disease.

Dr. Barrett's key contributions in the innovative use of non-ionic contrast media to prevent contrast nephropathy have made him recognized worldwide as the foremost expert on the subject. He has advanced understanding on topics in progressive chronic kidney disease and end-stage kidney disease.

Dr. Barrett has dedicated a substantial amount of his time serving on and elevating the Canadian research community through Kidney Foundation activities. These include serving as a member of the Biomedical Scientific Committee for seven years and acting as a member of the Foundation's Research Council, and of the National Medical Advisory Committee.









# Special Thank You to Volunteers from the Kidney Research Community

The Kidney Foundation appreciates the dedication and support of the 72 kidney researchers and 12 kidney patients that collectively volunteered more than 2,300 hours of their time to help the foundation meet its research goals this year. Their work and expertise contributed to the launch of a new Research Framework and to select the best scientific projects for funding in the Foundation three research competitions: the Biomedical Research Grants competition, KRESCENT and the Allied Health competition.

In 2019, our patient partners were involved as reviewers in the KRESCENT competition, acted as advisors to the KRESCENT curriculum, actively participated in workshops and provided strategic input to develop the Research Framework.

Thank you to our scientific and patient experts for all the hard work and help!

