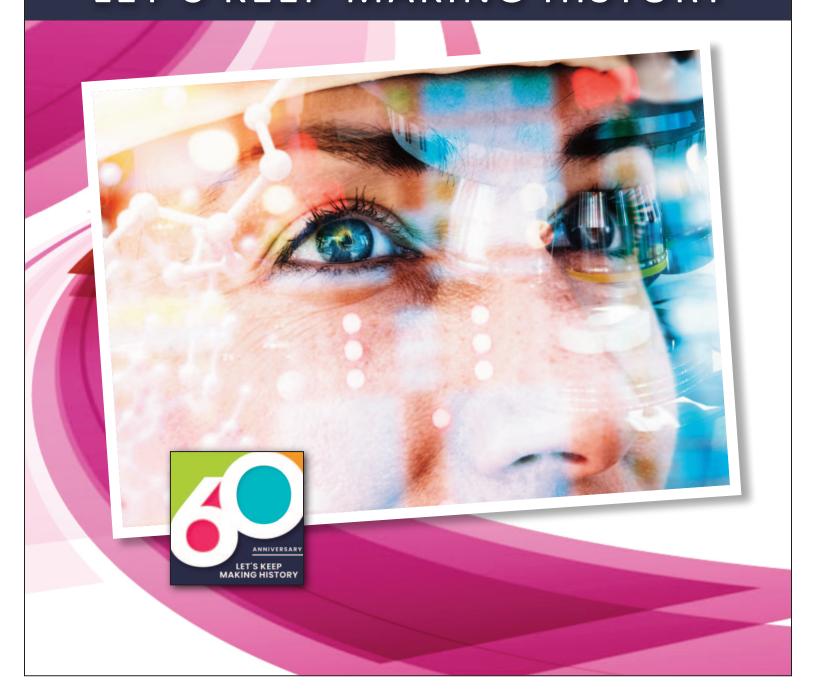


# LET'S KEEP MAKING HISTORY



### Our vision Our mission

Excellent kidney health, optimal quality of life for those affected by kidney disease, and a cure.

The Kidney Foundation of Canada is the leading charity committed to eliminating the burden of kidney disease through:

 Funding and stimulating innovative research for better prevention, treatments and a cure;

- Radius Control of the Control of the
- 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 health care;
- Increasing public awareness and commitment to advancing kidney health and organ donation.

The Bhal family participated in last year's Winnipeg Kidney Walk.

# Equity, Diversity & Inclusion Statement

Diversity is about what makes each of us unique – it's about all of the things that make us who we are. Embracing diversity celebrates that all of these things together make the whole much greater than the sum of the parts.

The Kidney Foundation embraces diversity and believes that all Canadians are equal and should be valued as individuals irrespective of their backgrounds. We will not tolerate discrimination of any kind and will maintain full compliance with provincial Human Rights legislation.

Discrimination has no place within The Kidney Foundation of Canada; we reflect this in our values, our attitudes, our policies, in all areas of our work and in what we do and say.

The Kidney Foundation is committed to embracing diversity, to fostering inclusion and to creating an environment free of discrimination and a world where everyone has access to treatment and care for kidney disease. Our staff and volunteers are committed to treating all our constituents, volunteers, donors, staff, stakeholders and supporters with respect and dignity.



The Kidney Foundation of Canada is a proud member of HealthPartners. HealthPartners is the only organization in Canada raising funds for nation-wide health charities through workplace giving. Donations to HealthPartners help 17 leading health charities, including our own, conduct critical research, develop support and education programs and find treatments and cures we need to save lives in our community.



The Kidney Foundation is a proud member of the Health Charities Coalition of Canada (HCCC). Founded in 2000, HCCC is a member-based organization comprised of national health charities and patient groups who represent the voice of patients at all levels of the health continuum. Our mandate is leading national collective action on health policy and health research to benefit patients living in Canada.

## Message from the President and National Executive Director





## LET'S KEEP MAKING HISTORY

n 2024, The Kidney Foundation of Canada celebrates its 60<sup>th</sup> anniversary. Back in 1964 when the Foundation was created, kidney failure was nearly always fatal, dialysis was just a temporary treatment option more suited to acute kidney failure than long-term treatment, and kidney transplantation was in its infancy. Treatment and care for people with kidney disease has come a long way since then, and so has The Kidney Foundation, evolving to meet our community's needs to ensure that people affected by kidney disease can live their best life.

Financially and operationally, 2023 was a very strong year for The Kidney Foundation. We raised more revenue than ever before, allowing us to invest more in research, programs, and services for those impacted by kidney disease.

We also made significant progress on our strategic plan priorities, including:

- Addressing access to our programs and services in underserved communities, and identifying underserved populations in order to help us find ways to better meet their needs
- Launching a pan-Canadian advocacy initiative, which has the potential to transform care for those affected by kidney disease in Canada
- Raising awareness of the risks and burden of kidney disease to educate and inform Canadians about kidney health and the work of the Foundation
- Maximizing our impact through improved systems and collaboration while maintaining our strong connection to our communities
- Recruiting and retaining our volunteers, who donate upwards of 41,000 hours of their time annually
- Investing in research and leveraging funding opportunities that have the power to transform care and improve outcomes for people affected by kidney disease

Based on our successes in 2023, we are poised for achieving even more in 2024 with our advocacy work, our 60<sup>th</sup> anniversary campaign, and the culmination of our strategic plan. With new treatment options and new data on early diagnosis, we are on the cusp of transformative advances for kidney patients and those at risk of chronic kidney disease.

Thanks to our many volunteers, donors, supporters, we made a difference for the 4 million Canadians with kidney disease.

We are very excited to celebrate how far our kidney community has come and how much care has improved. We can't wait to see what successes the next 60 years will bring. Together, let's keep making history!

KURTIS KRUG
PRESIDENT

ELIZABETH MYLES
NATIONAL EXECUTIVE DIRECTOR



# Peer support eases strain of dialysis

Greg and Barbara share their experience and encourage others through peer support.

reg and Barbara Halabut are familiar faces at peer support meetings organized by

The Kidney Foundation. Greg is in his late sixties and is on home hemodialysis. His wife Barbara retired from her job in finance to train with him on the home dialysis system and be Greg's caregiver. The Manitoba couple take part in several online meetings each month and find the sessions helpful.

"The biggest thing is the camaraderie with everybody," Greg noted. "People taking part are like-minded in most ways. It is always great because we can support others in the group and pick up bits and bites about things we didn't know."

His wife, Barbara, agrees: "Everybody has their own individual struggles, but we are on the same journey."

Greg remembers the exact day he started dialysis: October 12, 2017. It was a day that would change the course of his life and the lives of those around him. At first, he received in-clinic dialysis sessions three times a week. Then, a few months later, he and his wife Barbara completed training for home hemodialysis. At first, he dialyzed during the day but found it kept him at home too much. So, they switched to nocturnal hemodialysis and, despite

some initial hiccups, found the system is the best fit for their lifestyle.

"It frees up our day so we can go to the gym or go for a ride up in the country and get out of the city," Barbara said. "With nocturnal dialysis we can try to have a normal life."

They find speaking with others about their experiences helps them get through the day-to-day frustrations of living with kidney failure – both as a patient and as a caregiver. They also discuss topics such as new advances in dialysis technology at the meetings, and options for travel.

The Foundation has started online peer support meetings where people from across the country can join in. At these sessions, Barbara was surprised to learn how much dialysis services can vary from province to province.

"In Ontario some of the dialysis centres also offer nocturnal dialysis," Barbara said. "So if the patient doesn't want to dialyze at home, and give their caregiver a break, they can go into the centre. They can have their treatment and then come home in the morning and carry on with their day."

Greg is a big supporter of the online model for meetings, as "it opens up a whole new world" for people who might have trouble attending in-person. He looks forward to the sessions and encourages others living with kidney disease to consider signing up.

### ACCESS PEER SUPPORT FROM COAST TO COAST

A community of support is just a phone call or click away. The Kidney Foundation's peer support program is a key service where trained volunteers who either live with kidney disease or have been affected by the disease can help answer questions and share experiences in a safe, caring way. Group support is delivered virtually, making it accessible to everyone no matter where they live or where they are in their kidney journey.

Over the last four years, *Kidney Connect Peer Support* has expanded to include not only open groups, that work for everyone, but also now include specialized groups to meet more specific needs. Group sessions are just one place to find help and support. The Kidney Foundation also offers one-on-one phone sessions with trained volunteers.

No matter where you are on your journey with kidney disease, help is available. Call our Programs team at 1-866-390-7337 or email peersupport@kidney.ca for information about group meeting registration.

# One strong voice for kidney care in Canada

Ithough chronic kidney disease (CKD) is a critical and rapidly growing public health issue, it has not been recognized by key government agencies, initiatives, or plans. CKD is largely preventable and treatable and should receive greater attention in health policy decisions.

The Kidney Foundation of Canada is committed to addressing this by developing a national CKD framework that will transform kidney disease prevention, detection, and treatment in Canada.

"Canadians need and deserve equitable access to quality kidney care," said Carrie Thibodeau, National Director of Programs & Public Policy. "This CKD framework will play a critical role in ensuring that the needs of people at risk of, or living with kidney disease, along with their care partners, are met now and into the future."

Throughout 2023, the Foundation established key working groups and held extensive consultations with many members of the kidney

FONDATION DUTE IN KICINET FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED IN CARL KICINET FOUNDATION PRODUCED FOUNDATION FOUNDATION FOUNDATION FOUNDATION FOUNDATION FOUNDATIO

medical and allied health professionals, researchers, and those with lived experience. This important work is continuing to move forward in 2024.

On April 9, 2024, representatives from The Kidney Foundation's advocacy working groups, along with many volunteers, convened on Parliament Hill to meet with Members of Parliament and government officials to raise awareness of kidney disease and discuss the need for a national framework for chronic kidney disease.

"The day's meetings were a great success, and important connections were made with policymakers, marking a crucial step toward making meaningful change for people affected by kidney disease," said Elizabeth Myles, the National Executive Director of The Kidney Foundation.

From left to right, Kidney Foundation National President Kurtis Krug and National Director of Programs & Public Policy Carrie Thibodeau; Minister of Crown-Indigenous Relations Gary Anandasangaree; and Kidney Foundation National Executive Director Elizabeth Myles.

"The efforts of the team that day will result in multiple follow-up conversations, collaboration, and a heightened awareness of the prevalence, diagnosis, and treatment of CKD," added Ms. Thibodeau.

A survey aimed at those with lived experience of kidney disease and their caregivers is being deployed in May to further inform next steps in the development of the CKD framework.

"We are committed to this process," said Ms. Myles. "We must insist that CKD be recognized and prioritized as a public health problem in Canada so that all Canadians have access to quality kidney care."

Dedicated Kidney Community
Advisory Committee members,
pictured left to right:
Vanessa Tait, Sue Huffman,
Sean Delaney, Harroop Ahuja,
Vince Andrews and Dave McKeague.

Other members not pictured include Anne Huang, Francine Girard-Griffith, François-René Dussault, Nancy Verdin, Sylvie Charbonneau, and Teresa Atkinson.



# Reaching new heights in the battle against kidney disease



Volunteers conquered the mountain summit during the Chic-Chocs Grand Challenge, raising funds and awareness for The Kidney Foundation.

he Kidney Foundation has an amazing team of volunteers across the country. From walks to gala dinners, they raise vital funds and promote awareness of kidney disease and organ donation.

Most of the fundraisers take place over the course of an afternoon or evening. There are some events, though, that require a different kind of commitment – and a sense of adventure!

Pascal was planning an excursion to the Himalayan mountains when he saw the ad on Facebook. It was a fundraiser organized by The Kidney Foundation, for some hiking through Quebec's picturesque Chic-Chocs mountains

in the Gaspésie. Four summits in four days. As an avid mountain lover, it caught his attention.

Pascal, the founder of Ekitas law firm in Montreal, signed up. He hoped to raise \$50,000 in honour of his colleague Pierre, who was marking 50 years as a lawyer. Pierre has a long-standing interest and commitment to The Kidney Foundation and organ donation.

"One of his daughters lost her kidney function when she was young, and Pierre donated a kidney to her," Pascal explained. He could have offered Pierre a trip to the Bahamas or another gift to celebrate his 50 years at the Bar, but fundraising was way more meaningful.



Pierre was very touched by his colleague's decision to join the Chic-Chocs Grand Challenge: "I was very happy to support the Foundation, and the kidney patients it helps." Pierre's family has lived with the impact of kidney disease for decades. The organ he donated to his daughter began to fail a few years ago. She was on dialysis for a time but has since undergone a second kidney transplant and is doing well.

While Pascal took part in the four-day hike, Pierre was his partner on the ground. Many of Pierre's long-term clients, in appreciation of his decades of professional commitment to them, offered generous donations. In the end, the law firm surpassed its goal and raised nearly \$63,000 for The Kidney Foundation.

In another part of the country,
Alberta's Kidney March is a marathon
hike that promises a lot of fun
and maybe a few aching muscles.
Volunteers walk 100km in three
days, from the foothills of the Rocky
Mountains to Calgary. The March
raises funds to support kidney
patients, kidney research and organ
donation.

CONTINUED ON PAGE 7



aina and her husband Kris have taken part in the Kidney March for several years. Daina was diagnosed with kidney disease in 2014, after experiencing serious complications while pregnant. Her daughter was delivered early – at 27 weeks – and is in good health. After her pregnancy, doctors discovered Daina had a kidney disease called focal segmental glomerulosclerosis (FSGS).

"It was a very scary time," she recalled. "When you are diagnosed with a disease that doesn't have a cure it changes everything."

Four years after her diagnosis, Daina's father heard an ad on the radio about the Kidney March. They signed up together, with her father doing the full walk and Daina joining the support crew.

The March was life-changing; Daina discovered a community of people living through similar experiences.

"All the years from 2014 to 2018 I was fighting it alone; I didn't know there were other people my age battling kidney disease. I heard other peoples' stories about their struggles on the March, and didn't feel alone anymore," Daina said.

Her husband Kris joined the following year. He says he was quickly "adopted" into the March family and met other participants who have since become close friends.

"From a mental health standpoint, I don't think we would be nearly as healthy as we are today if we didn't have that community," Kris noted.



While the length of the hike makes it physically demanding, there are many opportunities to recharge along the route. Rest stops are available, and weary participants have access to hot showers and nutritious meals. Daina and Kris have great memories of the Marches they've been on, and feel it is an important way to support a better future for kidney patients.

"It is so important to volunteer because so many people are suffering from this disease," Daina reflected. "Volunteering for events not only raises money for a cure but it helps kidney patients not feel alone anymore."

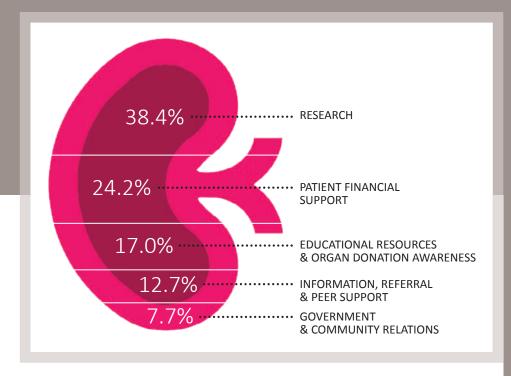
For her husband Kris, the event is a way to support his wife, who has gone through so much over the past decade.

"I am not a scientist, and I am not a doctor. This is the one thing caregivers can do to change the future for patients. Progress is being made and a lot of that progress is paid for from fundraising events like this one."



# Spending by program

hanks 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.



# 2023 Highlights

### 2023 KIDNEY WALKS\*



95
IN-PERSON AND
VIRTUAL WALKS
\* INCLUDES KIDNEY MARCH

**4,000** PARTICIPANTS

27,000 DONATIONS WERE MADE

\$3.3 MILLION FUNDS RAISED

## PROGRAMS & EDUCATION



5,460
RECEIVED SHORTTERM FINANCIAL
ASSISTANCE, TOTALING
\$938,000

4,260
ACCESSED PEER
SUPPORT PROGRAMS

55,183
EDUCATIONAL
MATERIALS DISTRIBUTED

**2,677**WEBINAR
PARTICIPANTS/VIEWERS

## ONLINE ENGAGEMENT



11,300 COMPLETED RISK AWARENESS QUIZ

78,000 CONNECT VIA SOCIAL MEDIA ENEWSLETTER SUBSCRIBERS

903,700 VISITORS TO OUR WEBSITES

81,500 SOCIAL MEDIA FOLLOWERS

#### VOLUNTEER SUPPORT



VOLUNTEER HOURS

We are grateful for the kindness and generosity of so many volunteers. You fuel success and inspire us all to achieve greatness.

Your leadership is valued. You make sure those impacted by kidney disease feel supported as part of the kidney community. Your commitment is impressive as you raise funds for research and programs. Your voice is heard as you continue to raise awareness about this serious health issue.

Thank you!

# KRESCENT Fellow wins inaugural CIHR Early Career Transition Award

Dr. Ayodele Odutayo, recipient of the inaugural CIHR REDI Early Career Transition Award.

r. Ayodele Odutayo (Women's College Hospital) is one of 43 candidates awarded in the inaugural CIHR research Excellence, Diversity and Independence (REDI) Early Career Transition award.

Dr. Odutayo, a KRESCENT fellow, was successful in the Kidney Health pool with the research project entitled "Expanding the use of SGLT-2 inhibitors to improve cardiorenal disease" and was ranked first in the award competition.

The Kidney Foundation of Canada is a proud partner in the inaugural CIHR Research Excellence, Diversity and Independence (REDI) Early Career Transition award. This award is targeted to support post-doctoral researchers,

clinicians and research associates from underrepresented groups launch their independent research careers in Canada. The award is a two-phase award, providing both salary support and research funding during the post-doctoral training in phase 1, and committed funding to support the launch of the candidate's independent research career through both salary support and research funding in phase 2.

The launch of this program comes from the recognition that the transition from post-doctoral fellow to independent researcher can be one of the most difficult hurdles to overcome in a researcher's career development. This can be made more difficult by the addition of systemic

barriers that are often in place for those from underrepresented groups, even though those very groups may often experience an over representation of many chronic diseases.

"The first launch of the CIHR REDI award addresses the impact of racism and gender inequality on early career researchers, with the aim to make a meaningful difference in the lives and careers of researchers facing systemic barriers," said Leanne Stalker, National Director of Research for The Kidney Foundation of Canada. "This aligns with The Kidney Foundation's strategic focus on capacity building and equity of access in kidney research."

eart disease and kidney disease are leading causes of poor health. While these conditions can occur separately, many people will have both medical conditions. The combination of heart and kidney disease is now known as a unique medical condition called "cardiorenal syndrome" and it results in frequent admissions to hospital for heart failure, worsening of kidney function and in some people, the need for dialysis. Improving our understanding of cardiorenal syndrome is an opportunity to improve heart and kidney health at the same time.

A new class of medications know as sodium glucose co-transporter 2 (SGLT2) inhibitors work by changing blood flow and pressure in the kidney (risk factors for kidney damage) and thereby reducing the risk of developing heart failure and/or worsening kidney function by up to 40%. These medications are only approved for a subset of people: those with diabetes, advanced kidney disease or heart failure. Given the effectiveness of SGLT2 inhibitors in preventing heart failure and worsening kidney function, these

medications may benefit other people that are at risk for these outcomes.

The goal of Dr. Odutayo's research is to understand whether expanding the use of SGLT2 inhibitors to new unstudied patient populations can prevent heart failure and kidney disease. This is because preventing disease would have a larger public health impact than selectively treating people after they have developed heart failure and advanced kidney disease. "The unstudied populations I will focus on are people with a recent heart attack and people without diabetes that have risk factors for cardiorenal disease like hypertension and early kidney disease."

### JOINING DR. ODUTAYO, WHO IS THE PROJECT LEAD, ARE THE FOLLOWING INVESTIGATORS:

#### **Primary Supervisor:**

Jacob Udell (Women's College Hospital)

**Co-Supervisors:** Husam Abdel-Qadir (Women's College Hospital), David Cherney (Toronto General Hospital), Michelle Hladunewich (Sunnybrook Research Institute)



# Hope through research

he Kidney Foundation of Canada has been a vital force in advancing kidney health. Its founding principles encompassed not only patient support but also a strong commitment to research. Over the years, the Foundation's research initiatives have led to significant advancements. These include better understanding of kidney function, improved dialysis techniques, and breakthroughs in transplantation medicine.

The research journey in the past 60 years started with a passion to find answers about kidney disease, grew quickly to make us a force for change in care and treatment through research investments. Ever since, this initial commitment has allowed The Kidney Foundation to leverage and spark new research channels and projects which strive for improved treatment, hope and a cure. We have consistently joined forces with other organizations and research institutions who share our common goal of making life better for all those impacted by kidney disease.

The past milestones noted here are a snapshot of the tireless work of many passionate researchers and allied healthcare professionals, who also lend us their volunteer time and commitment as we build stronger programs, like our celebrated KRESCENT program for new kidney researchers.

In our anniversary year, our investment in research since inception totals \$138.8 million, and millions more have been invested through leveraged opportunities.

As The Kidney Foundation looks to the future, there are key pillars to its research goals:

- Consistently funding research to improve prevention, diagnosis, treatment and wellness.
- Amplifying opportunities for investments into innovative projects through collaboration and leveraging funding opportunities to foster knowledge exchange, accelerate discoveries, and enhance patient care.
- Commitment to translating research findings into both knowledge and practical solutions for patients.
- Giving those with lived experience the opportunity to have a voice in research.

#### **RESEARCH MILESTONE MOMENTS**

- 1973 The organization was funding medical research into kidney-related diseases by allocating \$25,000 for grants.
- **1979** \$1 MILLION was allocated to RESEARCH.
- 1981 Kidney Foundation of Canada support for RESEARCH EXPANDED to include a Summer Student Program, and a Para-medical Council, which included nurses, social workers, dietitians and other allied health professionals.
- **1987** Kidney Foundation provides funding for over half of all non-governmental kidney disease research in Canada.
- 30th Anniversary and The Kidney Foundation boasts
  13 Branches and 93 Chapters across the country and
  over \$37 MILLION INVESTED IN RESEARCH to date.
  Also, the Foundation hosts a national dialysis symposium, and introduces an Endowment Fund.
- 1995 We hosted the Links to Success Forum. Together, 105 key stakeholders from government, healthcare institutions, the organ donor community and the Foundation itself, developed solutions to the critical shortage of organs in the organ donation process and proposed ways to work collaboratively. We responded to the organ donation crisis with implementation of the LIVES plan (Leadership Information Vital funding Education Special projects), empowering collaborative projects to significantly increase the number of organs and tissues available for transplantation in Canada.
- 1996 We launched the Medal for Research Excellence.
  Dr. David Z. Levine was awarded the recognition during this inaugural year.



- 1998 We hosted the Horizons 2000+ Conference. Its outcome: commitment to the development of a transdisciplinary, translational research training program to enhance capacity for kidney research in Canada (see www.krescent.ca).
- 2000 We organized a special research competition focused on organ donation. One of the successful outcomes:
  National Guidelines to Address Gaps in the Organ
  Donation Process, based on research by Dr. Sam Shemie.
- **2002** New Emerging Teams (NET) grants funded by The Kidney Foundation and CIHR become available.



Dr. Patrick Parfrey receives the Medal for Research Excellence Award. One of his projects, CANPREVENT (Canadian Prevention of Renal and Cardiovascular Endpoints), is among the six projects funded by NET.



CONTINUED FROM PAGE 10

Future discoveries could include new treatments, better outcomes for transplants and advancements in technologies and discoveries that can take advantage of new knowledge.

The last few years have been an exciting time in kidney research. New medications and treatment options have been approved in the kidney disease space for the first time in decades, and patient care is an ever-changing landscape. With technological advancement comes increased opportunity for innovation.

#### **IMPACT AND HOPE**

The Kidney Foundation of Canada Research program remains committed to staying at the forefront of kidney disease research, aligning our investments to patient and community needs, and focusing on where we can invest with the highest chances for impact.

There are opportunities to harness new technologies for personalized medicine, focusing on whole patient wellness through the kidney health journey. Through partnership and investment, we will encourage the employment of novel techniques and technologies for the treatment of kidney disease and transplantation, ensuring that our research program remains at the cutting edge of scientific development.

Most importantly, we will continue to support the engagement of our community in the research process, and in the dissemination of research results, ensuring that kidney patients and their families are positioned in a place of knowledge, and empowered to make informed health care decisions. This will allow us to ensure that our program continues to have real life impact for our patient community, and that research continues to bring hope for future generations.

2004



We launched the first competition of the newly created Kidney Research Scientist Core **Education and National Training** 

Program (KRESCENT) to cultivate the next generation of kidney researchers.

We hosted the Horizons 2015, a national research 2007 consensus conference to define research directions for the Canadian kidney health community and describe areas where capacity building is required to support the identified strategic directions.

2011



We partnered to support CANN-NET, a research network that links together Canadian kidney disease treatment

guideline producers, knowledge translation specialists, and knowledge users to improve knowledge dissemination and care of patients with kidney disease.

- We partnered with Kidney Cancer Canada and the 2012 federal government to support a national research network to promote research and develop resources to support the care and management of kidney cancer patients.
- The Kidney Foundation of Canada joins forces with 2013 The Macquarie Group Foundation (Australia) and The Alport Syndrome Foundation (U.S.) to undertake The Kidney Foundation's first international research competition into Alport Syndrome.
- We partnered with the federal government to support a 2013 MULTI-MILLION DOLLAR Canadian national transplant research program to address barriers to increase organ and tissue donation in Canada and enhance the survival and quality of life of Canadians who receive transplants.
- We worked in partnership to develop and fund World's 2013 First Gene Therapy Clinical Trial for Fabry Disease.
- **Canadians Seeking Solutions** 2016 and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) launches. Kidney Foundation has been a partner since inception.



EDKD / SUGARNSALT: We contributed a total of 2022 \$1 million over five years (2021-2026), matched by the CIHR, to fund a comprehensive research project called SUGARNSALT to accelerate research into diabetic kidney disease. Dr. David Cherney, Principal Investigator



of the SUGARNSALT project, is dedicated to find ways to prevent kidney failure and other serious complications in people with type 1 diabetes as they often do not get to benefit from the treatment innovations available to those with type 2 diabetes.



# We're here to help

rograms and services for The Kidney Foundation of Canada got their start with a focus on building knowledge and finding a way to be with patients every step of the way as they engaged in a kidney healthcare journey that included dialysis treatments and eventually, for some, consideration of a transplant.

The patient manual, as it was then called, was a binder that was carried to appointment after appointment, treatment after treatment, gathering new documents, appointment cards, recommendations and supplemental educational material along the way. Although the manual has changed many times in many ways over the years, it has remained a mainstay of The Kidney Foundation's commitment to provide basic medically-reviewed information to help explain the kidney disease journey.

Most people have never heard of kidney disease until it affects them or someone they care about. The Foundation is committed to helping patients locate the information and resources they need, learn more about how they can manage kidney disease, and understand the impact it has on their lives.

Over the years, growing needs were clear and in the early 1990s, The Kidney Foundation implemented new core programs across Canada to ensure that people had access to short-term emergency financial assistance and information and referral services. People affected by kidney disease and their caregivers needed somewhere to turn and someone to talk to.

Further, this led to the implementation of peer support programs, one of our key services today.

As our programs grew, so did our kidney community. Patients and caregivers have engaged in local programs and services through our many Branches and Chapters across Canada, and have been able to connect to other community organizations that support our goals to improve support, education, awareness and advocacy.

We have also looked for innovative solutions to provide customized information. The Kidney Community Kitchen is a tremendously popular site which helps people navigate a complex kidney diet, offering recipes for inspiration and advice from registered dietitians. Our new **kidneyinfo.ca** portal streamlines the kidney information highway for people seeking information about all stages of kidney disease.

#### PROGRAMS MILESTONE MOMENTS

- In recognition of the International Year of the Child, the FOUNDATION HELD ITS FIRST DIALYSIS CAMP in the Okanagan Valley of Kelowna, B.C. Camp Dialasun, as it was named, provided a unique vacation opportunity for children with kidney disease, ensuring medical needs could be met within the context of a regular camp atmosphere and program.
- 1982 The first edition of the Living With Kidney Disease PATIENT SUPPORT manual became available in both English and French.
- The Kidney Foundation Board endorsed three core "national" programs, delivered to constituents across the country: Short-term Financial Assistance, Living with Kidney Disease manual, and Information and Referral
- Our Living with Kidney Disease manual reached 5,000 people annually and was made available in 6 languages and on video cassette, audio tape, and in formats for the visually impaired.

1997



Two new resources became available for those supporting the pediatric population affected by kidney disease: Your Child and Kidney Disease and Childhood Nephrotic Syndrome.

- 1999 CRITICAL FINDINGS: We undertook a comprehensive survey, involving 18,000 patients across Canada, to assess educational and emotional support services. Findings revealed that a large group of patients live over 50 km from their treatment team and many are living below the poverty line. There was a critical shortage of: (1) kidneys for transplantation, (2) job retraining for people with end-stage renal disease, and (3) funds for research.
- **2005** We distributed the "Am I at Risk" brochure through Branches and Chapters.
- 2005 We launched the KIDNEY CONNECT







**CONTINUED FROM PAGE 12** 

#### THE FUTURE OF PROGRAMS

The Kidney Foundation of Canada Research program remains committed to staying at the forefront of kidney disease research, aligning our investments to patient and community needs, and focusing on where we can invest with the highest chances for impact.

There are opportunities to harness new technologies for personalized medicine, focusing on whole patient wellness through the kidney health journey. Through partnership and investment, we will encourage the employment of novel techniques and technologies for the treatment of kidney disease and transplantation, ensuring that our research program remains at the cutting edge of scientific development.

Most importantly, we will continue to support the engagement of our community in the research process, and in the dissemination of research results, ensuring that kidney patients and their families are positioned in a place of knowledge, and empowered to make informed health care decisions. This will allow us to ensure that our program continues to have real life impact for our patient community, and that research continues to bring hope for future generations.

Some of the directions of our current and future work include:

- Making our educational material accessible to an even greater number people affected by kidney disease across Canada
- Continuing to offer interactive webinars, workshops and forums that engage people with thought leaders and with one another
- Expanding the features and resources available on the Kidney Community Kitchen site
- Increasing our emphasis on mental and physical wellness as part of the healthcare journey by tapping into experts and those who have successes to share
- Providing opportunities to participate in classes, challenges or instructional sessions
- Enhancing peer support to address specific shared experience and topics of interest

Technological advancements will continue to open the door to new program opportunities, and sharing lived experiences with others will continue to be key priority for information and support.

- 2007 The Manitoba Branch launched the Island Lake Project, a curriculum designed for primary and secondary disease prevention, to help address the growing incidence of kidney disease in the Aboriginal community.
- 2007 Kidney Health Centre is piloted in Ontario to screen participants for risk factors for kidney disease.
- 2011 We launched the Kidney
  Community Kitchen,
  an online nutrition
  resource for people
  living with kidney
  disease, made possible



- through a bequest from the James Andrews estate (15,400 members as of 2024).
- 2011 We launched a NATION-WIDE TARGETED SCREENING PROGRAM to enable early detection of kidney disease and management of risk factors for the disease. (6,500 participants as of 2014)
- 2013 Kidney Foundation provides nearly \$1 MILLION in Financial Support to People Living with Kidney Disease.
- **2014** We launched our branded SOCIAL NETWORK, taking the Kidney Connect Peer Support Program online **kidneyconnect.ca**
- 2020 The impact of COVID brings new virtual program offerings to help those living with kidney disease feel supported and stay connected.



2024 We launched **KidneyInfo.ca**, a new portal dedicated to supporting patients and caregivers at every step in their kidney journey. The site offers resources specific to five pathways: chronic kidney disease,



living with kidney failure, dialysis, organ donation and transplantation, and conservative kidney management.



# One strong voice

dvocacy is a powerful tool for change. It involves speaking up for what you believe in and trying to persuade others to lend their support. The Kidney Foundation of Canada advocates on behalf of those affected by kidney disease to make positive change happen in policy development and best practices.

The Foundation has been a catalyst to encourage those with lived experience to have a voice in the decisions that directly impact their care, be it through self-advocacy or by adding their voices to others striving for systemic change.

As illustrated by many milestones along the way since The Kidney Foundation got its start in 1964, we have shown a commitment to amplifying voices, to finding opportunities to have decision makers listen to the needs of those impacted by kidney disease, dialysis, and transplant. Your voices have helped to create better healthcare for everyone.

Over the years, The Kidney Foundation of Canada has advocated for the development of formal organ donation agencies and renal networks that have led to systemic changes in how kidney failure is addressed in Canada. Many organ donation awareness campaigns and initiatives, including distribution of organ donation wallet cards, have been led by the Foundation.

The Kidney Foundation is a key participant in the national Organ Donation & Transplant Collaborative (ODTC), which was formed following the Minister of Health's Mandate Letter of October 2017. The ODTC's mandate is to "facilitate collaboration on an organ and tissues donation and transplantation system that gives Canadians timely and effective access to care". Volunteers and staff participate in numerous committees which address data collection, public awareness, and the engagement of those with lived experience.

We have intensified efforts to mobilize patients and families to be a leading voice in advocating for equitable access to transplants for all Canadians, for system improvements, and for greater accountability to ensure that no opportunities for deceased organ donations are missed.

#### **ADVOCACY MILESTONE MOMENTS**

- In order to maximize opportunities for Canadians and patients to respectively donate and receive lifesaving organs, The Kidney Foundation supported computerized retrieval programs across Canada to coordinate organ transplantation and tissue matching interprovincially and internationally. These programs included Alberta's Human Organ Procurement and Exchange (H.O.P.E.), the Multiple Organ Retrieval and Exchange (M.O.R.E.) in Ontario, Quebec's Metro Transplantation, the Maritime Organ Retrieval and Exchange (M.O.R.E.) and the Organ Procurement and Exchange of Newfoundland and Labrador (O.P.E.N.).
- The BC Branch successfully helped advocate for reversal of provincial decision, which did not allow payment for cyclosporine treatment for transplant recipients.
- 1987 Quebec succeeded in having an organ donation consent form placed on the back of newly issued medicare cards.



- 1987 Patient advocacy ensures that erythropoietin (EPO) is part of the provincial health services program.
- 1994 Child test-screening for urinary disorders is expanded nationally.



**CONTINUED FROM PAGE 14** 

Collectively, we will continue to raise awareness about important issues at all stages of kidney care and seek to influence the decisions of those who can lead change at every level of government and through every system that intersects with those living with kidney disease.

The Kidney Foundation also engages in partnership opportunities to lend our voice to general health-related matters that impact those with kidney disease or those at risk. Recent examples include our engagement to advocate for dialysis patients' access to the COVID vaccine, our participation in common drug reviews to champion equitable access to new medications, our call for improved phosphorus labelling, and an appeal to halt the marketing of unhealthy food and beverages to children.

Looking to the future, we will continue to focus on helping people find their voices and make them heard. Self-advocacy and the tools that empower people to listen, learn and make decisions about their own healthcare journey will continue to have a strong place in our patient educational materials and interactive forums. We will also encourage people affected by kidney disease to advocate for better access to care in the earlier stages of chronic kidney disease. One way we'll do this is to provide opportunities for people to interact and meet with federal, provincial, and territorial governments to share their experiences and perspectives.

The Kidney Foundation remains committed to amplifying the voices of those affected by kidney disease to make change happen. Together we can improve the lives of millions of Canadians.

2006 The BC Branch and BC Transplant Society jointly launched a 3-year pilot project:
Living Organ Donor Expense Reimbursement Program (LODERP) to reimburse living kidney and liver donors for expenses related to their gift of life, such as travel, accommodation and loss of income. This BC pilot project was used as a model to develop and implement similar programs across the country.

**2013** We partnered with the federal government to support a MULTI-MILLION DOLLAR Canadian

national transplant research program to address barriers to increase organ and tissue donation



in Canada and enhance the survival and quality of life of Canadians who receive transplants.

**2018** Kidney Foundation releases report on the Burden of Out-of-Pocket Costs for Canadians with Kidney Failure.

2021



The Kidney Foundation has implemented a top-up Wage Replacement Policy through its engagement with the Living Donor Circle of Excellence and becomes an official partner of the program in 2023.



## Awareness to spark action

ublic awareness about kidney disease and organ donation has been a key driver of The Kidney Foundation of Canada's mission for well over 50 years. Shortly after its inception, the Foundation took a leadership role in broadening Canadians' understanding of the importance of kidneys to overall health and encouraging discussion and decision about organ and tissue donation. What started as a campaign to share educational brochures has grown into an ongoing commitment to be the catalyst to bring kidney disease out of the shadows so it can be recognized for the serious health condition it is.

By building awareness of kidney disease, our actions have been designed to empower people to recognize symptoms early and to consider their personal risk which can help lead to early detection and preventative measures. It can also encourage people to think about lifestyle choices that could aid in prevention and improve overall wellbeing.

Kidney Foundation campaigns connect people with information they need to take action. Our online risk awareness tool guides thousands of people annually to think about their kidney health. Using public polling about kidney awareness, the Foundation has navigated a sea of healthcare information for Canadians who are encouraged to keep kidneys top of mind for their health.

Complementing messages about kidney disease and maintaining kidney health is our commitment to organ donation awareness.

With a vast majority of people on the transplant waiting list needing a kidney – a statistic that has not changed much over these many years – the Foundation has consistently led organ donation awareness initiatives and has regularly amplified others' efforts to do the same.

#### **AWARENESS MILESTONE MOMENTS**

- **1974** Information brochures on kidney disease and dialysis became available to the public at large.
- **1974** In 1974 alone, the Foundation distributed more than a MILLION organ donor cards.
- 1979 March was officially declared Kidney
  Health Month in Canada and dedicated
  to increasing public awareness of kidney
  disease and raising funds for research.
- 1980s In the 1980s, it was estimated that 1 MILLION CANADIANS suffered from one form or another of kidney disease. The Kidney Foundation stepped up its efforts to increase awareness and reduce the burden.



- A nationwide PUBLIC RELATIONS CAMPAIGN was mounted profiling four people "living with kidney disease", helping to put a face on the "one in a million" Canadians directly affected. The campaign included newspaper and magazine ads as well as television and radio placements.
- **1985** Over 1 MILLION wallet-sized cards were distributed, explaining the warning signs of kidney disease.
- **1987** The Foundation becomes an active member of the Canadian Coalition on Organ Donor Awareness.
- 2009 Kidney Foundation's Great Canadian Kidney Quiz shows 60% of Canadians are unable to identify diabetes or high blood pressure as the two major causes of kidney failure.



2009 To sensitize Canadians to the importance of kidney health, we developed new public awareness campaigns. We also launched the Kidney Stories of Hope Awareness Campaign to encourage e-testimonials from people personally touched by kidney disease.



**CONTINUED FROM PAGE 16** 

Well before the establishment of many organ donation agencies, in 1985 The Kidney Foundation took initiative to distribute a million organ donation wallet cards in that one year alone, encouraging people to declare their decision to be a lifesaving donor. In more recent years, our partnership with Green Shirt Day and our engagement with organ donation agencies and like-minded organizations from coast to coast has multiplied our efforts to ask people to make a positive decision in registering their wishes. Kidney Foundation messaging has also consistently emphasized the important need to proactively discuss that decision with family members so they can honour one's wishes.

More recently, we became an early adapter of the Living Donor Circle of Excellence, a program which encourages employers to close a financial gap for individuals who choose to be a living organ donor. We are encouraging businesses and other organizations to follow suit.

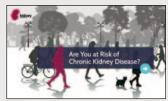
The Kidney Foundation of Canada is committed to continue to lead the charge in these awareness arenas.

By engaging those with lived experience and other ambassadors for kidney health and organ donation, we develop messages that meet the needs of communities and builds public education opportunities.

We will continue to seek out partnerships which build kidney health and improve organ donation rates.

We will communicate our commitment to be there every step of the way for those impacted by kidney disease for life.

The Kidney Foundation of Canada makes your kidney health a priority. You can count on us to make sure kidney health and organ donation is part of the conversation. 2014 We launched an online risk awareness tool for kidney disease: available in four languages at www.kidney.ca/risk (nearly 20,000 visits in 6 weeks)



- 2014 Launch of public service announcements to promote awareness of risk factors for kidney disease and the newly available online risk assessment tool for kidney disease.
- 2020 We joined Green Shirt Day as an official partner in raising awareness of organ and tissue donation.



# Interactive online platforms promote kidney health



ani Renouf is passionate about helping kidney patients eat well and enjoy the meals they make. The renal dietitian's love of food has led her to co-host, with Anja Webster, a program called "Come Cook with Us" on the **Kidney Wellness Hub** website – live from her very own kitchen. Kidney patients can log in and cook alongside Dani and Anja. They can also ask questions live during the session.

Dani Renouf

"Food brings us together," Dani noted.
"I love being able to show kidney patients that cooking can be fun and joyful."

The cooking show is a popular feature of the Kidney Wellness Hub and a great extended use of the content available through the Kidney Community Kitchen website. The interactive hub, launched in 2022, features a range of online activities, from dance to art classes and yoga. It was developed by The Kidney Foundation BC & Yukon Branch in

response to a survey of kidney patients, caregivers, and health care partners.

"Some patients we connected with were feeling isolated and in need of customized resources to support their overall well-being," said Deborah Tucker, Senior Communications and Marketing Director at the Foundation's BC & Yukon Branch. "The Kidney Wellness Hub offers a welcoming space where kidney patients can come together and find community."

The Hub focuses on healthy eating, staying active, improving mental health, and building social connections.

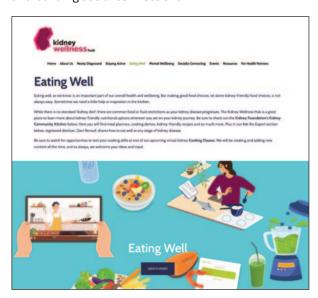
A diagnosis of kidney disease can be overwhelming, and this new portal aims to make the process of seeking out facts about the condition easier. It is designed so that, whatever stage of kidney disease you are facing, you can find relevant information quickly and easily.

"One of the key features of the portal is that it is organized according to where people are on their kidney journey," said Carrie Thibodeau, National Director of Programs and Public Policy. "You can click on a pathway, and all the resources in that area will relate

to your stage of kidney disease."

Users can access five specific pathways on the site: Chronic Kidney Disease, Kidney Failure, Dialysis, Organ Donation and Transplants, and Conservative Kidney Management. The portal provides up-to-date information on nutrition, physical and mental health, and other areas such as advocacy and kidney research. Users can also connect with

the Kidney Community Kitchen and peer support programs directly from the home page.



The Kidney Foundation launched another new interactive site in early 2024, called **kidneyinfo.ca**. It provides a central online space for Canadians to access kidney health information and resources and is available in both English and French.

The Kidney Foundation launches new awareness campaign

Volunteers
participating
in the filming
of our new PSA.

journey with chronic kidney disease is not the same for everyone, but the shared experience binds those affected. Kidney disease is always there, demanding attention from every part of you. It's relentless. It interrupts. It upsets. It harms.

The Kidney Foundation launched a new public service announcement (PSA) in 2023, directed by kidney transplant recipient, Jesse Hunt and the team at Campsite. Jesse was able to draw on his lived experience with kidney disease from dialysis to transplant to the ever-present stresses of living with this disease. The takeaway message is one of hope and support. It is our hope that viewers learn that The Kidney Foundation of Canada is with you for life, beside you each step of the way on your journey with kidney disease, no matter your experience.

In creating the new PSA – simply titled "with you", many volunteers stepped up to participate in the filming so that the message could make an even bigger difference. Volunteer Jason Lumb shared how

much he valued the experience:

"Public messaging is vitally important for The Kidney Foundation. We need to get the word out, so that people

diagnosed with kidney disease and their families know that programs and services exist to help them wherever they are in their kidney journey. I hope that the PSA attracts a lot of people

to the Foundation so they can get the support they need."

The PSA was filmed in Hamilton, Ontario over two days in January 2023. It was particularly meaningful to see the camaraderie among the volunteers and the pride that each person felt throughout the filming.

"It was fascinating to me to see if all come together," added Jason. "Most of us were kidney patients and it was wonderful that we were included in this campaign." Our PSA highlighted the Foundation's commitment to providing support for those living with kidney disease.



In May the campaign hit airwaves nationwide and the Foundation participated in several national media interviews to further the conversation, highlighting the impact of kidney disease and how our programs and services can help those living with and affected by kidney disease.

The PSA and related lived experience stories can be viewed at **kidney.ca/withyou**.

Research investment made in 2023: \$4,264,744\*

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

Cumulative investments since 1964: \$138.8M

PHOTO CREDIT: SHUTTERSTOCK



### New strategies to battle kidney stones



**DR. INDRA GUPTA** 

ust one occurrence of kidney stones results in a 50 per cent chance of recurrence and raises the chances of severe kidney damage. Given these risks, finding ways to prevent the common condition is a priority, says Dr. Indra Gupta, a paediatric nephrologist.

Gupta and a team of researchers at The Research Institute of the McGill University Health Centre are looking at genes called claudins to see if they might identify who is at risk of developing the condition and aid in its prevention.

Claudin genes help make proteins of the same name that cover the body's barrier surfaces including those of lungs, skin, and kidneys. In the kidney, these protein molecules line the filters (nephrons) and clear waste from the body. Stones form when these filters fail to eliminate calcium from the blood properly. The condition affects 12 percent of men and six percent of women.

Gupta's team is exploring whether people with kidney stones have changes in the DNA that encodes claudin genes that alter how the kidney eliminates calcium. They will also evaluate whether a traditional natural remedy used to treat kidney stones is effective since scientific proof is lacking. Some evidence suggests that the remedy prevents kidney stones by modifying the claudin proteins' function in the kidney filters. If found effective, the researchers will standardize the remedy's preparation.

The need for a new treatment approach is important because existing prevention strategies are far from satisfactory, Gupta says. The effectiveness of a major medication to prevent stone formation has recently been questioned. Standard dietary treatments, such as increasing water consumption or reducing salt and protein intake, are hard to maintain. "Because of their work, their life, people can't manage the standard diet for the long term, or they forget to do it, and another stone slowly forms," she says.

Made from the leaves of Bryophyllum pinnatum, a plant indigenous to Haiti and many other countries, the traditional remedy is a tea and simple to administer. "The time is right to do the tea trial, and I think the time is right to try to understand kidney stones," Gupta says.

Acute kidney injury: is the follow-up happening?

DR. NGAN LAM

ore than half of people who receive in-hospital critical care will experience acute kidney injury. However, few of these patients receive complete follow-up care, concludes a 2023 study by nephrology and critical care researchers at the University of Calgary and the University of Alberta.

The three-year study began in 2021 and analyzed information from the Alberta Kidney Disease Network for nearly 30,000 critically ill patients who had experienced acute kidney injury while in intensive care between 2008 and 2019. Only one in four had obtained both the blood and urine tests needed to assess their kidneys' performance.

Treatment guidelines recommend that people who have experienced such an injury undergo testing within three months after a hospital discharge. Testing is essential because other research shows that people who experience acute kidney injury while hospitalized, including in intensive care, are likely to experience greater risks of more injury occurring or chronic kidney disease.

While 64 per cent of those studied did obtain a blood test, only 28 per cent obtained the urine test. "We were hoping most people would have had both measurements," Dr. Ngan Lam says, one of the researchers involved in the project. Most people did see a physician within three months, as recommended. Five per cent of these visits were with a nephrologist—a kidney specialist.

Because the study used databases that remove identifying information, such as individual patient charts, it's difficult to pinpoint the exact reasons for the low rates of testing. "We can hypothesize, but we don't know for sure why," Lam says.

The study's second stage, now under way, involves determining how to fix the issue. Examining whether follow-up care positively influences longer-term outcomes is another research priority. Lam anticipates the study's second phase will be completed and published by the end of 2024.

Lam, a nephrologist and associate professor at the University of Calgary, notes that Dr. Rachel Jeong spearheaded the project as part of her Masters candidacy. The project was a collaborative effort but it was born out of Dr. Jeong's passion for nephrology and critical care, Lam says.

Funding from the Foundation's Kidney Health Research Grant program made the project possible. "I was very grateful for its help to get results about this and to help fund Dr. Jeong's research training as well," Lam says.

# Transplant education for children



#### DR. HOLLY MANSELL

nformation about kidney transplants is abundant, but sifting through that volume can challenge anyone searching for specifics related to their situation. Even more daunting is finding information that is age appropriate.

Few educational materials about receiving a new kidney are tailored for children and youth because their numbers needing a transplant are small. Each year, only 50 to 60 children undergo renal transplants in Canada.

Adapting the materials is necessary because "information needed for an 18-year-old may not be appropriate for someone who is six, nor can it be presented in the same way," explains Dr. Holly Mansell, an Associate Professor in the University of Saskatchewan College of Pharmacy and Nutrition.

To address the gap, Mansell and other Saskatchewan researchers are developing a mobile application. Called HELP (Health Education and Learning Platform), the app will draw on a content library comprised of existing and newly developed materials designed to help the young recipients on their complex journey. Previous studies by the group have shown that educational materials improve patient knowledge and satisfaction but tailoring these resources to the appropriate audience remains a challenge. The researchers anticipate that an app supplying timely, relevant, and relatable information to younger patients and their families will ease anxiety and improve the transplant experience.

"We can put different things into the library," says Mansell. "So, for instance, maybe it's important to explain the immune system to a caregiver and a child, but you would explain it in different ways that resonate with each of them." Animations are particularly useful educational tools because it is easy to change their scripts and wording to reach people of different ages.

The research group is developing the application with the assistance of patients and their caregivers. Currently, they are compiling the library. Testing begins once the library is completed, about a year from now, and will involve distributing the app to families and their professional caregivers in six health services across Canada. The team will modify the app based on the feedback received.

Mansell credits the Allied Health Kidney Research Grant for providing critical support for the development of the library and the app's final stages of testing and modification. "We have an idea for an app and are starting to develop it, but it's nothing if you can't test it and get it to the right people to try it out."

# Gut health in chronic kidney disease



**DANI RENOUF** 

eople living with kidney disease often struggle with nutritional deficiency. Sometimes, the problem arises from an overly restricted diet based on out-of-date information. Other times, the condition itself creates the deficiency.

Recently, researchers in British Columbia began to explore whether protecting the gut microbiome might help address the issue. "Patients wanted this question answered," says Dani Renouf, a registered dietician involved in the the BC Renal network's renal collaborative research group.

Medical research has long established connections between the gut microbiome—the bacteria in our digestive systems—and overall health. A good balance of bacteria helps prevent toxin buildup in our bodies and ensures that we make the most of our nutrition.

But when people experience health problems such as chronic kidney disease, levels of harmful bacteria can increase, and related inflammation can also affect the gut. "We believe that if these people had better nutrition, they might have better gut health, which may translate to better overall health," says Renouf.

The two-year study begins this year and involves three components. First, researchers will gather data on the gut health and eating habits of people with kidney disease and not on dialysis. (People receiving dialysis develop a different gut microbiome, and this microbiome has undergone considerable study.)

Then, they will compare the physical data with the nutritional records to identify connections. The third objective of the study is to assess the impact of nutritional supplements on the gut microbiome.

Researchers will begin the study at two hospitals in Vancouver and expand research across the province to examine the impact on people in remote areas where access to nutrition may differ.

Healthcare providers working in full-time clinical care have devised the study in partnership with patients, and the multidisciplinary approach involves specialists in nephrology and the gut microbiome, as well as dieticians and statisticians. Renouf says the Allied Health Kidney Research Grant makes this innovative collaboration possible. "I don't think there are many grants like this one."

She hopes the study will ultimately lead to the development of markers of nutritional problems that can provide more individual therapeutic approaches for people with kidney disease. "If we know certain significant differences, that will get us closer to precision nutrition," she says.

# Volunteers drive research forward

he Kidney Foundation of Canada's research program wouldn't be possible without the hours of dedication from all our volunteers.

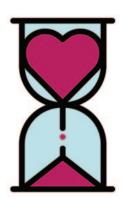
Clinicians, researchers, allied health professionals, partners and people with lived experience contribute valuable hours out of their busy schedules to help our program succeed in the goal of funding and supporting excellent, innovative research from coast to coast, providing education on kidney health and disease, and building capacity in kidney research in Canada.

From participating on peer review committees and reviewing and assessing applications for excellence to contributing to KRESCENT workshops or webinars we are thankful for every hour that our community dedicates back to our program. We couldn't do it without you!

In 2023, the research department accrued over **2,450 hours** of volunteer time. If you spread that out over the year, that's more than six hours a day!

We would like to take the time to thank each of our volunteers for all their time, effort, and hard work.

## VOLUNTEER ENGAGEMENT IN RESEARCH (IN HOURS)



1,106

KIDNEY HEALTH RESEARCH GRANTS

<u>682</u>

KRESCENT PROGRAM AND WORKSHOPS

/10

KRESCENT GRANTS

•

ALLIED HEALTH

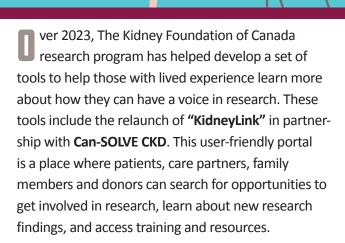
IZU

GRANTS

96

RESEARCH COUNCIL

**TOTAL: 2,645 HOURS** 



We have also launched a new "lived experience in peer review" training module to help introduce members of the community to the process of peer review, as we broaden our engagement of lived experience experts on our peer review panels.

These resources are a step in continuing to build engagement of those with lived experience to our research community.

# Get involved

If you are a person with lived experience who is interested in participating in The Kidney Foundation of Canada's research program, but you aren't sure where to start, please visit our "engage in research" section on our website, or reach out to: Leanne Stalker,
National Director of Research at

leanne.stalker@kidney.ca

# 2023 New funded researchers by program



#### KIDNEY HEALTH RESEARCH GRANTS



MOHSEN AGHARAZII Co-Applicants: Darren Richard, Etienne Audet-Walsh,

Fabrice Mac-Way, Richard Larivière Université Laval, QC 2023-2025: \$120,000

#### **PROJECT TITLE:**

Hydrochlorothiazide and accelerated CKD-related vascular calcification

#### CATEGORY:

- Chronic kidney disease
- Hypertension



SAMANTHA ANTHONY, SARA AHOLA KOHUT Co-Applicants:

Ashley Audrain, Catharine Dunn, Dr. Chia Wei Teoh, Eleanor Pullenayegum, Jennifer Stinson, Katherine Cost, Melanie Barwick The Hospital for Sick Children, ON 2023-2025: \$120,000

#### **PROJECT TITLE:**

Addressing the mental health needs of parents of pediatric kidney transplant recipients with the iParent2Parent peer support program

#### **CATEGORY:**

- Quality of life
- Underserved communities
- Transplantation



TOM BLYDT-HANSEN Co-Applicants:

Dr. David Wishart, Fabian Eibensteiner, Gabriela Cohen, Karen Sherwood, Li Wang, Mei Lin Bissonnette University of British Columbia, BC 2023-2025: \$120,000

#### **PROJECT TITLE:**

Multiomic characterization of chronic, active T cellmediated rejection in pediatric kidney transplant recipients

#### **CATEGORY:**

- Transplantation
- Predictive biomarkers



JOHN CHAN Co-Applicant: N/A Université de Montréal, QC 2023-2025: \$120,000

#### **PROJECT TITLE:**

Molecular mechanism(s) of intrarenal RAS regulation of sodium-glucose co-transporter 2 (Sglt2) expression in diabetic kidney CATEGORY:

- Chronic kidney disease
- Diabetes
- Hypertension



JEFFREY DICKOUT Co-Applicant: N/A McMaster University, ON 2023-2025: \$120,000

#### PROJECT TITLE:

Targeting CHOP expression to prevent ischemic AKI CATEGORY:

Acute kidney injury



MEGHAN ELLIOTT, KRYSTINA LEWIS Co-Applicants:

Clara Bohm, Danielle Fox, Gregory Hundemer, Jennifer MacRae, Maoliosa Donald, Matthew James, Pietro Ravani, Rob Quinn University of Calgary, AB 2023-2025: \$120,000

#### **PROJECT TITLE:**

Individualizing vascular access selection: an examination of current practices to support shared decision-making

CATEGORY:Chronic kidney disease



### MARIE-CHANTAL FORTIN, HOLLY MANSELL

#### Co-Applicants:

Heloise Cardinal, Jagbir Gill, Mary Beaucage, Nicola Rosaasen, Rahul Mainra, Serge Pierre Centre Hospitalier de l'Université de Montréal, QC 2023-2025: \$119,964

#### PROJECT TITLE:

Identifying and addressing the educational needs of patients from historically marginalized groups on less than ideal kidneys

#### **CATEGORY:**

- Patient care
- Transplantation
- Underserved communities



#### TYRONE HARRISON Co-Applicants:

Brenda Hemmelgarn, Cheryl Simoens, Danielle Fox, Maoliosa Donald, Matthew James, Meghan J. Elliott, Ms Nancy Verdin, Navdeep Tangri, Nicole Brockman, Paul Ronksley, Shannon M Ruzycki University of Calgary, AB 2023-2026: \$180,000

#### **PROJECT TITLE:**

Person-centred perioperative risk prediction for people with kidney failure **CATEGORY**:

- Chronic kidney disease
- Dialisys
- Population health





TANIA JANAUDIS-FERREIRA Co-Applicants: Chelsia Gillis, Franco Carli, Jean Tchervenkov, Marie-Chantal Fortin, Stephanie Thompson The Research Institute of the McGill University Health Centre, QC 2023-2025: \$119,900

#### PROJECT TITLE:

Virtual home-based physical pre-habilitation in kidney transplant candidates: a pilot RCT CATEGORY:

- Transplantation
- Quality of life
- Chronic kidney disease



ANDRAS KAPUS Co-Applicant: N/A St. Michael's Hospital, Toronto, ON 2023-2025: \$120,000

#### PROJECT TITLE:

Altered mitochondrial dynamics and the underlying molecular mechanisms in polycystic kidney disease CATEGORY:

- Kidney biology
- Chronic kidney disease



CHRISTOPHER KENNEDY Co-Applicant: Dylan Burger Ottawa Hospital Research Institute, ON 2023-2025: \$120,000

#### **PROJECT TITLE:**

Molecular mechanisms of Childhood Idiopathic Nephrotic Syndrome

#### **CATEGORY:**

- Chronic kidney disease
- Kidney biology



ANA KONVALINKA Co-Applicants: Lisa Robinson, Markus Selzner University Health Network, ON 2023-2025: \$120,000

#### **PROJECT TITLE:**

Hepatocyte Nuclear Factor 4 Alpha (HNF4A) as a regulator of kidney graft repair

#### **CATEGORY:**

- Transplantation
- Chronic kidney disease
- Acute kidney injury



**CAROLINE LAMARCHE Co-Applicant:** N/A
Hôpital MaisonneuveRosemont, QC
2023-2026: \$180,000

#### PROJECT TITLE:

Regulatory T cells (Tregs) impact and role in chronic kidney disease

#### **CATEGORY:**

- Chronic kidney disease
- Dialysis
- Health policy



BRUNO LARRIVÉE Co-Applicants: Casimiro Gerarduzzi, Erika Hooker Hôpital Maisonneuve-Rosemont, QC 2023-2025: \$117,878

#### PROJECT TITLE:

Evaluation of the role of Alk1 signaling in the development and function of the glomerular endothelium CATEGORY:

- Chronic kidney disease
- Diabetes



ISTVAN MUCSI, BETH EDWARDS, DOUGLAS LEE Co-Applicants: Aisha Lofters, Josephine Etowa, Ms Maria Koh, Paula Neves, Princess Okoh, Tabo Sikaneta University Health Network, ON 2023-2025: \$119,736

#### **PROJECT TITLE:**

Access and barriers to advanced kidney failure therapies among patients from African, Caribbean and Black communities in Ontario CATEGORY:

- Chronic kidney disease
- Underserved communities



YASSER RIAZALHOSSEINI Co-Applicants: Janusz Rak, Simon Tanguay The Royal Institution for the Advancement of Learning/ McGill University, QC 2023-2025: \$119,900

#### PROJECT TITLE:

Liquid biopsy analysis to refine prognosis in renal cell carcinoma CATEGORY:

- Cancer
- Genetics
- Screening & prevention of renal disease



ROLA SALEEB Co-Applicants: Georg Bjarnason, Kelsie L. Thu St. Michael's Hospital, Toronto, ON 2023-2026: \$180,000

#### PROJECT TITLE:

The problem of non-clear cell renal cell carcinoma; tailoring the treatment to the biology **CATEGORY**:

- Cancer
- Chronic kidney disease
- Urology



STEPHANIE THOMPSON Co-Applicants: Aminu Bello, David Collister, Marcello Tonelli, Natasha Wiebe, Russell Greiner, Scott Klarenbach University of Alberta, AB 3/31/2023-3/30/2025: \$102,091

#### PROJECT TITLE:

Predicting individual risk of peripheral arterial disease and its complications in hemodialysis: evaluation of machine learning approaches

#### **CATEGORY:**

Dialisys



SEYCHELLE YOHANNA
Co-Applicants:
Amit Garg, Barb Longo, Catherine
Clase, Christine Ribic, Eric McArthur,
Jasper Ho, Jessica Sontrop, Jian
Roushani, Kyla Naylor, Richard Hae,
Shahid Lambe, Sue Mackenzie
McMaster University, Faculty of
Health Sciences, ON

#### PROJECT TITLE:

2023-2025: \$120.000

Outcomes of the one-day living kidney donor candidate assessment clinic

#### **CATEGORY:**

- Transplantation
- Chronic kidney disease
- Organ donation

#### ALLIED HEALTH KIDNEY RESEARCH GRANTS



**DIANA MAGER Co-Applicants:**Caroline Richard, Peter Senior
University of Alberta, AB
2023-2025: \$112,816

#### **PROJECT TITLE:**

Impact of food insecurity on adherence to diet quality, adherence to prescribed nutritional therapies and co-morbid disease expression in adults with Chronic Kidney Disease

#### **CATEGORY:**

- Quality of life
- Patient care
- Underserved communities



**HOLLY MANSELL Co-Applicants:**Allison Cammer, Chia Wei Teoh,

Jenny Wichart, Julie Strong, Kayla Flood, Keefe Davis, Lorraine Hamiwka, Michelle Ruhl, Natasha Minakakis, Nathaniel Osgood, Taylor Raiche, Tom David Blydt-Hansen, Veronique Phan University of Saskatchewan, SK 2023-2025: \$120,000

#### PROJECT TITLE:

Individualizing pediatric kidney transplant education with HELP (the Health Education and Learning Platform)

#### **CATEGORY:**

- Transplantation
- Patient care



DANI RENOUF, ADEERA LEVIN Co-Applicant: N/A University of British Columbia, BC 2023-2025: \$120,000

#### PROJECT TITLE:

Describing gut microbiota in people with chronic kidney disease

#### **CATEGORY:**

- Renal failure
- Patient care
- Predictive biomarkers

#### ALLIED HEALTH KIDNEY SCHOLARSHIP



ERIN McCONNELL
Dalhousie University, NS
Supervisors:
Christine Cassidy,
Audrey Steenbeek
2023-2024: \$5,000

# PROJECT TITLE: Transitions in transplant CATEGORY:

Nursing

#### KRESCENT NEW INVESTIGATOR AWARD



**TYRONE HARRISON**University of Calgary, AB 2023-2026: \$210,000
Infrastructure: \$25,000

#### **PROJECT TITLE:**

Improving perioperative risk prediction for people with kidney disease CATEGORY:

Chronic kidney disease



PING LIU University of Calgary, AB 2023-2025: \$195,000 Infrastructure: \$25,000

#### **PROJECT TITLE:**

Promoting shared decisionmaking for people with advanced CKD

**CATEGORY:** 

Chronic kidney disease



THOMAS MAVRAKANAS

The Research Institute of the McGill University Health Centre, QC 2023-2026: Curriculum only Infrastructure: \$25,000

#### PROJECT TITLE:

Novel therapeutic strategies in cardiorenal medicine CATEGORY:

Chronic kidney disease

# KRESCENT ALLIED HEALTH KIDNEY DOCTORAL AWARD

KRESCENT IS A NATURAL PARTNERSHIP

OF THE KIDNEY FOUNDATION AND THE CANADIAN SOCIETY OF NEPHROLOGY



REETINDER KAUR Supervisors: Jagbir Gill, Fuchsia Howard University of British Columbia, BC 2023-2026: \$105,000

#### **PROJECT TITLE:**

Factors influencing a woman's decision to become a living kidney donor: How to mitigate potential coercion **CATEGORY**:

Organ donation

# KRESCENT POST-DOCTORAL FELLOWSHIP



KYLE MEDAK Supervisor: Daniel Drucker Lunenfeld-Tanenbaum Research Institute, Mount Sinai Hospital, ON 2023-2026: \$165,000 (additional external support)

#### PROJECT TITLE:

Role of the vascular smooth muscle GLP-1 receptor in renoprotection

#### **CATEGORY:**

Diabetes



CHRISTIE RAMPERSAD

**Supervisor:** Joseph Kim University Health Network, ON 2023-2026: \$195,000

#### **PROJECT TITLE:**

Better decisions for better outcomes from deceased donor kidneys

#### **CATEGORY:**

Transplantation



MAGDALENA RIEDL KHURSIGARA

**Supervisor:** Anna Greka Broad Institute Inc., MA 2023-2026: \$165,000

#### **PROJECT TITLE:**

Molecular regulation of trafficking misfolded proteins to the lysomes **CATEGORY**:

Kidney biology



VICTORIA RIEHL-TONN Supervisor: Sofia Ahmed University of Calgary, AB 2023-2026: \$105,000

#### **PROJECT TITLE:**

Sex and gender considerations in patient outcomes in individuals living with chronic kidney disease CATEGORY:

Chronic kidney disease

# THE CANADIAN DONATION AND TRANSPLANTATION RESEARCH PROGRAM (CDTRP) PARTNERSHIP INNOVATION GRANTS



MAUREEN MEADE McMaster University 2023-2024: \$30,000

#### **PROJECT TITLE:**

Guidelines for sequential participation of transplant recipients into donor intervention trials and subsequent transplant trials

#### **CATEGORY:**

Organ donation



MURDOCH LEEIES University of Manitoba 2023-2024: \$30,000

#### **PROJECT TITLE:**

Sexual orientation and gender identity in Organ and Tissue Donation and Transplantation (OTDT): A curriculum in cultural competency for OTDT healthcare teams in Canada CATEGORY:

Organ donation

# Dr. Andrey Cybulsky 2023 MEDAL FOR RESEARCH EXCELLENCE

"Dr. Cybulsky's body of research is an essential resource for the exploration of new methods to tackle kidney disease. The Medal for Research Excellence provides us with a great opportunity to highlight significant achievement and a lifetime of commitment. Basic research is important to gain an overall understanding of kidney function and disease, and it adds to the building blocks on which the field improves the lives of patients through informing changes to clinical care.

The Foundation remains committed to supporting all forms of kidney research and strives to help build excellence in the kidney field." - ELIZABETH MYLES, NATIONAL EXECUTIVE DIRECTOR, THE KIDNEY FOUNDATION OF CANADA

s a clinician-scientist,
Dr. Cybulsky has made
significant discoveries
about the biology of podocytes.
These specialized cells support
the structure and function of the
kidney's glomeruli — filtration
units in nephrons (the kidney's
million tiny filters). Podocytes
help regulate blood filtration
and are the target of injury in
glomerular diseases.

Much of his work has focused on the mechanisms of injury in glomerular diseases, and specifically how podocytes are injured. The goal is to understand better both the routes leading to injury and the processes activated to reduce injury or protect injured cells.

"Over the years, we have characterized several cellular pathways in podocytes," explains Dr. Cybulsky. "These

have included protein kinases, stress pathways, and pathways involving lipid metabolism. We study how these pathways collectively maintain the functions of podocytes and how they are dysregulated in disease."

Supporting others early on in their careers is another of Dr. Cybulsky's priorities, and to date, he has mentored more than 50 graduate students and post-doctoral fellows, many of whom have won prestigious awards and gone



on to build their own successful careers in nephrology basic science research.

In addition, through his publications, which include 90 original peer-reviewed articles and 30 review papers, as well as through his involvement in organizing international meetings such as the 12th International Podocyte Conference in 2018, he has contributed substantially to the sharing of knowledge in his field.

# SUGARNSALT research expands through \$9M U.S. investment

Dr. David Cherney

n January 2024, JDRF, the leading global type 1 diabetes (T1D) research and advocacy organization, awarded \$9 million US to researchers Dr. Alessandro Doria with Joslin Diabetes Center, Dr. Michael Mauer with the University of Minnesota Medical School, and Dr. David Cherney at the University Health Network, University of Toronto, to conduct a pivotal clinical trial that will test sotagliflozin, a dual sodium-glucose cotransporter (SGLT)1 and SGLT2 inhibitor, in the treatment of kidney complications in people with T1D.

The study will build on the SUGARNSALT research project first led by Dr. Cherney, which is supported by a \$1 million commitment from The Kidney Foundation of Canada (KFOC) matched by a \$1 million investment by the Canadian Institutes of Health Research (CIHR) through the Team Grant: Diabetes Mechanisms and Translational Solutions competition, launched in 2022.

SUGARNSALT is one of the largest T1D focused kidney disease studies in the world, and it is the only phase 3 clinical trial targeting major kidney disease outcomes. This trial represents the collaboration of highly experienced clinical researchers and academic centers in the United States and Canada, most of whom have worked together successfully on a previous clinical trial. All recognized the opportunity to enhance the impact of the trial by joining together.

This trial will add to the SUGARNSALT project by testing the safety and effectiveness of an SGLT inhibitor in slowing the further loss of kidney function in people with T1D and kidney disease. A top line goal of the study is to provide data demonstrating a positive benefit of sotagliflozin for people with T1D who are suffering from diabetic kidney disease and which could support regulatory consideration in that population.

"While major advances have been made for the treatment of kidney and heart complications in people with type 2 diabetes over the last five years, treatment has remained unchanged in people living with type 1 diabetes for more than 20 years," said Dr. David Cherney. "As a result, the risk of complications remains unacceptably high. SUGARNSALT represents an unprecedented opportunity to determine if SGLT inhibition can reduce the risk of kidney disease progression in people with type 1 diabetes at the highest risk of future kidney failure."

The trial will be conducted at sites across the U.S. and Canada; enrollment was expected to begin in May 2024.

"Scientific advancement through collaboration increases opportunity and fosters innovation and progress," said Elizabeth Myles, National Executive Director of The Kidney Foundation of Canada.

"The Kidney Foundation of Canada is proud to be one of the founding partners on this significant investment to support innovative strategies to treat diabetic kidney disease. This new leveraged investment will bring this important work one step closer to treatment improvements for the patients we serve. We look forward to continuing to work with CIHR, as well as JDRF on this novel trial and to support this now multi-national project to achieve its goals."

sugarnsalt
is one of the largest
T1D focused kidney
disease studies in
the world, and it is
the only phase 3 clinical trial
targeting major kidney
disease outcomes.

Over the past 15 years, we have built a unique network of clinical investigators in the U.S. and Canada, who share the goal of finding new treatments to prevent or slow down kidney function decline in type 1 diabetes. I am thrilled to continue to work with such an amazing group of researchers in this new clinical trial," said Dr. Alessandro Doria.

#### **National Board** of Directors

**NATIONAL PRESIDENT** Kurtis Krug

NATIONAL IMMEDIATE PAST PRESIDENT Sylvie Charbonneau

NATIONAL TREASURER Patrice Waché

Cindy Pope

NATIONAL DIRECTOR -ATLANTIC CANADA BRANCH ONTARIO BRANCH

**NATIONAL DIRECTOR -BRITISH COLUMBIA AND** YUKON BRANCH Glenn Powers

NATIONAL DIRECTOR -MANITOBA BRANCH Donn Pirie

NATIONAL DIRECTOR -**NORTHERN ALBERTA AND** THE TERRITORIES BRANCH **Terry Tomkins** 

NATIONAL SECRETARY **Elaine Andrews** 

NATIONAL VICE-PRESIDENT Vince Andrews

NATIONAL VICE-PRESIDENT Annora Gilliam

NATIONAL DIRECTOR -Norm Muirhead

NATIONAL DIRECTOR -QUEBEC BRANCH Patrice Waché

NATIONAL DIRECTOR -SASKATCHEWAN BRANCH Leonard Blocka

NATIONAL DIRECTOR -SOUTHERN ALBERTA BRANCH Mike Sheppard

NATIONAL DIRECTOR-AT-LARGE Dr. Marie-José Clermont

NATIONAL DIRECTOR-AT-LARGE Rahil Dattu

NATIONAL DIRECTOR-AT-LARGE Sofia Kamran

NATIONAL DIRECTOR-AT-LARGE Alex Kolodkin

NATIONAL DIRECTOR-AT-LARGE Gilles Levasseur

NATIONAL DIRECTOR-AT-LARGE Kendra McPherson

NATIONAL DIRECTOR-AT-LARGE Trionne Phillips

NATIONAL EXECUTIVE DIRECTOR Elizabeth Myles

#### **Branch Office** Contact Information

**BRITISH COLUMBIA** 

AND YUKON BRANCH 200 - 4940 Canada Way Burnaby, BC V5G 4K6 604-736-9775 / 1-800-567-8112

info.bcy@kidney.ca Pia Schindler, Executive Director

**NORTHERN ALBERTA AND** THE TERRITORIES BRANCH

11227 Jasper Ave., Suite 202 Edmonton, AB T5K 0L5 (780) 451-6900 /1-800-461-9063 within Alberta & Territories info.nabt@kidney.ca Flavia de la Fuente, Executive Director

SOUTHERN ALBERTA BRANCH

6007 1A Street SW Calgary, AB T2H 0G5 403-255-6108 / 1-800-268-1177 info.sab@kidney.ca Joyce Van Deurzen, Executive Director

SASKATCHEWAN BRANCH

A3-116 103 Street East Saskatoon, SK S7N 1Y7 (306) 664-8588 / 1-833-664-8588 within Saskatchewan info.sk@kidnev.ca Joyce VanDeurzen, Executive Director

#### **MANITOBA BRANCH**

209-2211 McPhillips Street Winnipeg, MB R2V 3M5 204-989-0800 / 204-989-0815 info.mb@kidney.ca Greg Unger, Executive Director

#### **ONTARIO BRANCH**

1599 Hurontario Street, Suite 201 Mississauga, ON L5G 4S1 1-905-278-3003 / 1-800-387-4474 ontario@kidney.ca Anthony Tirone, Executive Director

#### **QUEBEC BRANCH**

880-5160 Decarie Blvd. Montreal, QC H3X 2H9 514-938-4515 / 1-800-565-4515 infoquebec@kidney.ca Elsa Desjardins, Executive Director

ATLANTIC BRANCH OFFICE

PO Box 13381 St John's, NL A1B 4B7 709-753-8999 / 1-800-563-0626 infoatlantic@kidney.ca Rosanna Mitchell. Executive Director



NATIONAL OFFICE

5160 Decarie Blvd., Suite 880 Montreal, QC H3X 2H9 514-369-4806 1-800-361-7494

www.kidney.ca

Charitable Registration Number: 10756 7398 RR0001

The Kidney Foundation of Canada's audited financial statements are available online at www.kidney.ca/about-us