



Message from the President and National Executive Director

ptimizing performance and impact by identifying priorities and setting a strategy to make a measurable difference has been a key objective for The Kidney Foundation in recent years. In 2017, a significant amount of commitment and passion from volunteers and employees brought forth a new strategic vision and performance assessment goals.

This strategy and vision was built around a powerful nucleus - those people affected by kidney disease. We are working to ensure that improved outcomes for people with kidney disease are front and centre when we are making decisions. Our strategic priorities align with this approach:

- → Improve patient outcomes and find a cure through strategic investment in research
- **Optimize** our support programs to best meet the needs of those impacted by kidney disease
- **Empower** people to manage their kidney health through accessible, relevant education and risk awareness
- → **Drive** policy and systems change by advocating effectively to governments and other organizations for equitable access to all treatment options

Research continues to be a core priority for The Kidney Foundation; in 2017 we funded \$3.4 million of research projects, and leveraged an additional \$10 million. Our support of patient-oriented research is grounded in the multi-million dollar Can-SOLVE CKD initiative that aims to transform kidney disease treatment by 2021. The Canadian National Transplantation Research Program (see page 13) is another strong network focused on transplantation research. Together, we are changing the future for people with kidney disease.

Our programs are evolving to ensure funding investments are made in the areas that will have the greatest impact on patients' lives. These include our peer support program, which offers patients the support of someone who has also experienced kidney failure, and can help those who are newly diagnosed get back on their feet and ready to fight back against kidney failure.

Consultations with our stakeholders confirmed that prevention and kidney health were important priorities for The Kidney Foundation. Through our risk awareness tools, we are reaching out to more Canadians at risk. In 2017, nearly 15,000 people used our online risk awareness tool to identify risk factors they should consider.

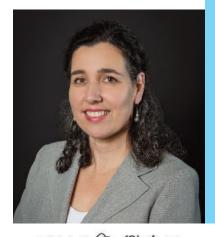
Another identified key priority was to focus more on the advocacy efforts needed to bring about policy changes at the provincial and federal levels. Our recent study on the financial burden of kidney disease will continue to inform our work in this regard.

We thank the volunteers, donors and partners of the kidney community for their ongoing commitment to help us deliver on our promise. We know that together, with your help, we can create a bold new future with positive outcomes for those living with kidney disease.

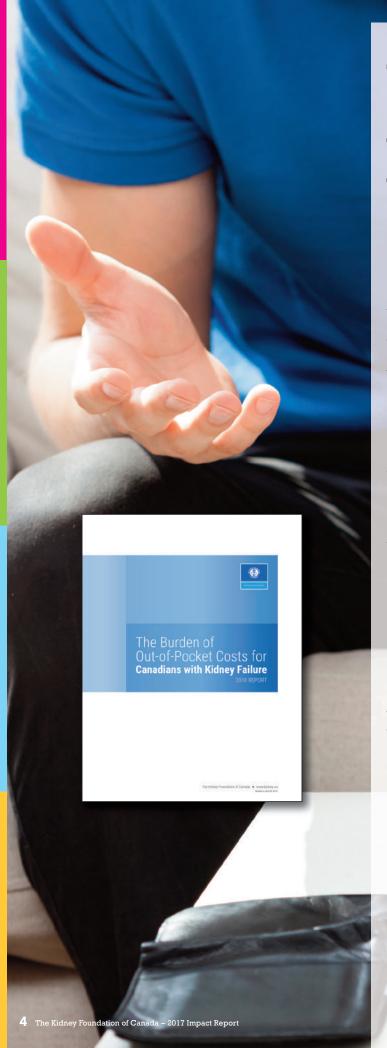
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NATIONAL PRESIDENT



comobon nuls Elizabeth Myles NATIONAL EXECUTIVE DIRECTOR



Addressing the Financial Burden of Kidney Failure on Patients

or many years, staff and volunteers at The Kidney
Foundation of Canada heard anecdotal accounts
of the heavy financial impact that a kidney failure
diagnosis could engender. Dialysis treatments are
typically required at least three times per week, each
one lasting between three and four hours. As a result,
the ability to work a full-time schedule is often compromised
and the household income drops significantly. Compounding
the problem, Canadians coping with kidney failure had to
dig into their pockets in order to access the life-sustaining
treatments they required.

It had become evident that a problem existed, and the time had come to have a closer look at its extent so that solutions could be found.

The Kidney Foundation partnered with the Canadian Association of Nephrology Social Workers (CANSW) to administer a survey of Canadians on dialysis. The survey was conducted online and via paper-based questionnaires in over 20 centres and was available in English, French and Chinese. The data was analyzed in association with Dr. Scott Klarenbach, Professor in the Department of Medicine at the University of Alberta in 2017.

The reported annual average out-of-pocket costs related to dialysis treatment ranged from \$1,400 to \$2,500. The out-of-pocket costs represent a considerable percentage of total household income, when you consider that 55% of respondents reported an annual household income of less than \$35,000 and 23% reported an annual household income of less than \$20,000.

"Disparities between jurisdictions in coverage for medications and home hemodialysis costs for people with end-stage kidney disease can form the basis of provincial advocacy plans for The Kidney Foundation of Canada," said Dr. Joanne Kappel, the Foundation's National Programs Committee chair. "Peer pressure is often a very good means to change behaviour and policy."

Based on the survey's findings, The Kidney Foundation of Canada is making the following recommendations to all levels of government to address the financial burden of kidney failure:

- → **Subsidize** transportation costs and expand access to travel grants, particularly for people in rural areas.
- → Minimize disparities in accessing medications for people with kidney disease and develop mechanisms to offset costs equitably across jurisdictions.
- → Provide adequate support for home dialysis through reimbursing utility costs and considering the financial and health literacy of patients when operationalizing "home first" policies.

Learn more in The Burden of Out-Of-Pocket Costs for Canadians with Kidney Failure report at **kidney.ca/burden**.

Transportation Assistance Provided a "Second Chance in Life"

ob is one of the thousands of Canadians who has benefited from short-term financial assistance from The Kidney Foundation of Canada. The Strathmore, Alberta resident says the Foundation "stepped up to the plate" to offer support at a difficult time when his kidneys were failing.

"They gave me my life back," Bob says, on the help he received from The Kidney Foundation that enabled him to take part in a home dialysis training program. "I couldn't ask for anything more. They gave me a second chance in life."

Bob discovered he had polycystic kidney disease (PKD) in 2009. The long-time truck driver was too sick to continue his work and money was tight. When his kidney function dropped to just seven per cent, it was vital that he begin dialysis. There was no dialysis centre in his community, and he could not afford to travel to Calgary for treatments. Home hemodialysis was his best option, but it would mean passing a certification course in Calgary. He would need to make a 100km return trip every day for six weeks to get the training he needed.

"I wouldn't have been able to do the course because I couldn't afford the travel to get there." he says. "The Foundation covered the cost of the transportation service. They picked me up at 6:30 in the morning and brought me back home at 6:30 at night."

During the first part of the program, there was a setback. Bob was rushed to hospital with what appeared to be a heart attack. It turned out to be a false alarm - he was suffering from anxiety. By then, he had missed the first two weeks of training. The Kidney Foundation was there to help him out, he recalls, by extending the funding for his transportation service to accommodate his illness. At a time when he felt weakened by poor health and money was tight, "the financial assistance from The Kidney Foundation helped me get back on track."

Today, Bob is continuing home hemodialysis treatments. He is working to raise awareness of kidney disease and has become an advocate for Canadians on dialysis. He believes the shortterm assistance he received through The Kidney Foundation has led to long-term benefits. He is now better able to shoulder the economic burden of kidney disease and manage his health.

- Article by Heidi Westfield



Bob and his wife Pat.















consulted KidneyCommunityKitchen.ca



accessed peer-to-peer support through **Kidney Connect**

Risk **Awareness** Core to Community **Education**

ducation programs are key to help prevent kidney disease, especially among at-risk populations. Unlike many diseases, kidney disease often has no noticeable symptoms until it is advanced. If caught in the early stages, kidney disease can be treated very effectively so it's important for people to become aware of their risk and, if they are at risk, get their kidney function tested.

The Kidney Foundation is committed to educational events held in partnership with at-risk communities, which are identified as those with higher rates of diabetes and hypertension, namely people of Asian/South Asian, African/ Caribbean, Hispanic, Indigenous, Pacific Island descents and those 65 years of age and older.

Information on the risk factors for kidney disease, early warning signs of reduced kidney function and self-advocacy strategies are provided to participants. Additionally, data on understanding commonly-used medical terms, and accessing local healthcare and other programs is also provided. Organ and tissue donation information and education is often included. In many cases, these educational opportunities are built in conjunction with other Kidney Foundation events or through invitation from other community services and partners.

In 2017, Kidney Foundation volunteers and staff participated in 140 health information-related events.

Complementing the community-based program, an online education component about risk factors has been an important resource

in educating people about the underlying causes of kidney disease. The quiz, available

at kidney.ca/risk, was updated to provide more detailed information on some risk factors.

assessed their risk of kidney disease at kidney.ca/risk

Increased marketing of the quiz resulted in an unprecedented number of visitors in 2017.

New TV Program Generating a Lot of Buzz

hat's a great way to promote kidney health and organ donation? Launch a grassroots television program that raises awareness of kidney disease with interviews, field segments, and a serious dose of fun.

The Kidney Foundation's BC & Yukon Branch began producing PLUGGED-IN for Shaw TV in 2016. The half-hour show is

broadcast across British Columbia and Yukon, on Shaw Direct across Canada. and on YouTube. The program includes an upbeat mix of expert interviews, personal stories, health advice, game shows - even Sidney the Kidney has his own segment!

"On any given day, a half hour show is airing somewhere in British Columbia delivering exposure we have never had before," says Barbara Valentine, Senior Manager of Marketing and Promotions for The Kidney Foundation of Canada, BC & Yukon Branch. "It's an entertaining and very informative way of providing information about kidney health, kidney disease, and organ donation."

Foundation communications staff members host the program, with the Burnaby office serving double-duty as a studio for the tapings. They are supported by some high-profile volunteer talent, including actor William Stewart and

broadcaster James Cybulski. While the production is staffed mostly by volunteers, there is a limited budget for film crew, editing, and on-location segments in the field.

Last summer PLUGGED-IN went on the road, sharing the stories of people living with kidney disease in a number of communities. The hosts travelled everywhere from Penticton in BC's interior to Comox, on Vancouver Island, Shaw TV provided volunteer camera staff in the communities they visited. The program is connecting with audiences beyond the kidney community, helping generate better awareness of the Foundation and kidney health.

doctors, to patients, to social workers, transplant recipients, and the general public." - Barbara Valentine, The Kidney Foundation of Canada, BC & Yukon Branch Dr. Mike Bevilacqua MD, FRCPC **Deb Tucker** Fraser Health

"We are talking to

"I love the fact that it provides a platform to be out on the street in different places," Barbara notes. "We are talking to doctors, to patients, to social workers, transplant recipients, and the general public."

In just a few years, PLUGGED-IN has gained a higher profile and is reaching a greater audience. Along with being broadcast on community channels in BC and Yukon, the program was recently picked up for Shaw's Multicultural Channels in Vancouver and Calgary.

- Article by Heidi Westfield



Kidney Mortgage: A Unique Way to Give Back



Supporting The Kidney Foundation's Mission

There are many ways to support The Kidney Foundation's mission of eliminating the burden of kidney disease that extend beyond making a donation.

Personal Online Fundraising Page → Celebrating a birthday, an upcoming wedding, or the anniversary of your kidney transplant? Be a Hope Hero by creating your own fundraising page

Kidney Mortgage → The Kidney Mortgage team is striving to impact change with a \$1,000,000 partnership with The Kidney Foundation of Canada. To reach this goal, \$224 will be donated for each successful completion of a Kidney Mortgage! The Kidney Mortgage program is available in British Columbia, Alberta, Saskatchewan,

Kidney Clothes → If your drawers are overflowing and your closets are in chaos, it might be time to consider a donation to Kidney Clothes. We will turn your used clothing donation into much needed funds for kidney research and educational programs that help fight kidney disease.

The Kidney Clothes program is available in Calgary and

Kidney Car → The Kidney Foundation's Kidney Car program is a simple, quick and convenient way to dispose of your unwanted vehicle. You will receive a valuable tax receipt for your car and we will tow it away for free. Proceeds from donated vehicles help ensure that The Kidney Foundation can continue to provide hope and support to thousands of Canadians living with and at risk of developing kidney disease. The Kidney Car program is available in most areas throughout the country.

Tributes → Make a donation to honour someone who is celebrating a special occasion (such as a wedding anniversary, transplant anniversary, birthday, or bar/bat mitzvah) or in memory of someone who has passed away.

uying your first home is a life-altering event. It's a major milestone that's not to be taken lightly. Thirty-year-old Meghan knew from the start she needed help navigating the big decisions, like negotiating her mortgage. On the advice of her mom, Meghan sought the expertise of a Kidney Mortgage broker. In doing so, she also made it possible to alter the lives of others with kidney disease.

The Kidney Mortgage program is a new and innovative way for people to get an important service while also supporting The Kidney Foundation of Canada. Each mortgage purchased through Kidney Mortgage provides a \$224 donation to The Kidney Foundation (at no cost to the donor) for research, programs, and organ donation awareness activities. Why \$224? Every two weeks, 224 Canadians are diagnosed with kidney disease. As a member of Canada's largest brokerage, the Kidney Mortgage team can help negotiate a competitive rate.

"Participating in the Kidney Mortgage program allowed me to support The Kidney Foundation as a young donor," says Meghan. "And I was able to buy my first home with expert advice from the Kidney Mortgage team."

"We're pleased to receive the support of the program," says Joyce Van Deurzen, Executive Director of The Kidney Foundation's Southern Alberta & Saskatchewan Branches. "It's a simple, unique way for people to support our mission while getting a service they need anyway."

Best of all, Meghan bought a place that has become a true home. "I am so close to downtown I can bike to work. I love the neighbourhood, and I love my home," she smiles.

The Kidney Mortgage program is available in British Columbia, Alberta, Saskatchewan, and Manitoba.

> Planned Giving / Leaving a Gift in your Will → For many individuals, a will provides a means of continuing a commitment to a worthy charitable organization, such as The Kidney Foundation of Canada.

Advocate → Advocacy is the act of supporting or arguing in favor of a cause, policy or idea. Its goal is to influence public opinion and societal attitudes (e.g., by promoting organ donation) or to bring about changes to government, community or institutional policies.

Volunteer → Being a volunteer at The Kidney Foundation means joining a dynamic and diverse group of people who share a common purpose - to make a difference in the lives of others. We invite you to join thousands of people from across Canada who are making an important contribution to improve the lives of people with kidney disease.



ust after sunrise last July, six endurance swimmers ventured out into the cool waters of Lake Muskoka for a 30km relay event. It was the second Organ Donor Swim organized to raise awareness of organ donation and kidney disease. Along the route, cottagers and their guests on shore and in boats cheered on the athletes, with hundreds more offering support.

Toronto's Ricky Jacobs has seen the fundraiser, which began in 2016, gain remarkable momentum in a short time. Hope Heroes, a web fundraising tool available through The Kidney Foundation of Canada, provided a simple way to reach out to friends and family in his circle. The swim has so far raised more than \$30,000 to provide subsidies for children with organ transplants or living with organ failure to attend summer camp. One of the swimmers, Wendy Chong-Edgell, was able to raise \$10,000 of that total.

The relay swim is bringing attention to an issue that Ricky believes isn't addressed enough - organ donation. To help

people like his father, who is on dialysis and on

the donor kidney waiting list, Ricky would like Canada to adopt two significant initiatives: a living organ donor registry and an organ donor opt-out option, whereby people are presumed to give consent to be organ donors unless they have registered their wishes to opt-out.



43 Kidney Pages

created

"I love my father and want him to stay with us for a long

time," Ricky reflects. "We are a close-knit family that likes to take action and not sit idly by. Our hope at first was to do something to stimulate a conversation about organ donation as broadly as possible, and to try find a donor for my father."

Ricky came up with the idea for a relay swim symbolizing the different levels of people involved in organ transplantation. He chose to centre the fundraiser in Muskoka, which holds a lot of happy

Organ Donor Swim organizer Ricky Jacobs, at right, gives a high five to fellow participant Scott, as they make their way through Lake Muskoka.

family memories. He partnered with The Kidney Foundation for support and connected with competitive athletes in his circle, including an open water swimmer who competed in the 2012 Summer Olympic Games.

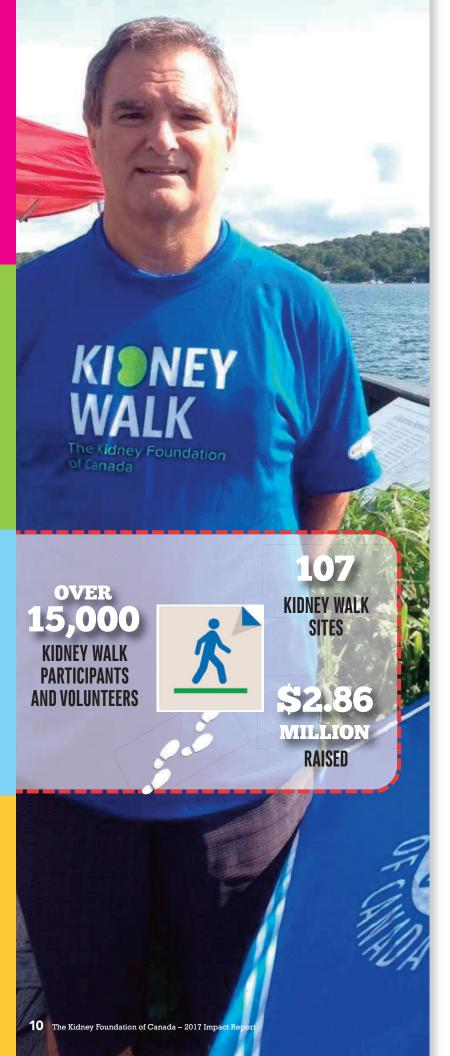
Volunteers in the Gravenhurst area rallied around the cause, offering accommodation, meals, medical/therapeutic assistance, and more. What started out as a conversation in a family living room has become a significant fundraiser that illustrates what individuals can accomplish with a shared purpose.

"Hopefully, people are talking about organ donation in ways that they weren't previously," Ricky says. "We look forward to building this event year to year and to focus on trying to make as much of an impact as we can."

- Article by Heidi Westfield



This dedicated group took to Lake Muskoka in what has become an annual event to raise funds and to increase awareness for organ donation.



Walks: a Fun Way to Raise Awareness

fter hearing about the Halifax Kidney Walk through an acquaintance, Steve decided to sign up and take part in 2017. He collected \$1,600 for The Kidney Foundation of Canada – the highest amount raised by a single participant in his location.

"I enjoyed it, it was fun," he says, of the Foundation's annual fundraiser along the east coast city's scenic harbourfront. "I met other people living with kidney disease. There were also nurses from the hospital taking part."

Steve has lived with high blood pressure for decades, and in 2013 that health condition led to kidney failure. He spent four and a half years on dialysis, the latter part on home hemodialysis. It was a difficult time made harder because the physical challenges of dialysis aren't easily visible to others. He recalls what it was like running into friends after dialyzing: "They'd see me walking around town after my treatment and say, 'Hey Steve, you look great.' And it's like, I feel terrible."

The 58-year-old former airport duty manager from Dartmouth, N.S. believes the Kidney Walk offers a unique opportunity to help raise awareness of kidney disease and organ donation.

"If I can get involved, and get my family and friends involved it helps spread the word. I think education is the big thing. People don't realize what people on dialysis go through."

This past February, Steve received a kidney transplant through the national Kidney Paired Donation (KPD) program. He travelled to Toronto for the surgery, and The Kidney Foundation of Canada offered financial assistance to subsidize the trip. The transplant was a success.

"The kidney worked great right away – it was instant. My creatinine level dropped phenomenally," Steve says. Despite feeling lethargic occasionally, his quality of life has improved dramatically since the transplant. He can drive again and has gradually reintroduced some of his favorite food into his diet, like shrimp and lobster. He is looking forward to swimming this summer and travelling with his wife Joanne.

Steve will be taking part in the next Halifax Kidney Walk, this time as the event's Honorary Chair. He has boosted his personal fundraising goal and is encouraging more friends and family to take part. The more interest the event generates, he says, the more Canadians will learn about kidney disease and the importance of organ donation.

Article by Heidi Westfield



rgan donation is a subject that hits close to home for Don Cherry and his family. His son Tim was diagnosed with kidney disease when he was 15. Cindy Cherry turned out to be an ideal match and donated a kidney to her little brother. Ever since, the family has made it a priority to help build awareness around organ donation and transplantation.

Throughout the 2017-18 season, Western Hockey League teams participated in RE/MAX Presents: WHL Suits Up with Don Cherry to Promote Organ Donation, a series of events across the WHL to promote the importance of organ donation and to generate support for The Kidney Foundation of Canada.

During the 17-game series, 1,000 fans at each game received a special Don Cherry bobble head, while everyone in attendance received a limited-edition Don Cherry trading card. On the ice, WHL players sported their own unique Don Cherry-themed uniforms. Fans bid on the jerseys, with all the proceeds going to The Kidney Foundation. Fans also got the chance to bid on Don Cherry-autographed jerseys in each participating WHL market. The 2017-2018 WHL season campaign raised \$265,500 for The Kidney Foundation and over 78,000 hockey fans had the opportunity to learn about the importance of organ donation.

The October 14 game pitting the Moose Jaw Warriors against the Vancouver Giants was particularly meaningful to the Stewart family. Their 18-year-old son Josh became an organ donor after an automobile accident and changed the lives of five people, giving each of them a second chance at life. His parents, Sandra and Brad, dropped the puck at the start of the Warriors game.

"Brad and I are always ready to do anything in Josh's name. It's always a very emotional experience," says Sandra, holding back tears. "Working to promote The Kidney Foundation and organ donation is a way for us to pay tribute to his memory." The couple has a long history as active volunteers for The Kidney Foundation of Canada, having hosted a Fun Run, and four A-Mooseing Race fundraisers.

Brad and Sandra Stewart drop the puck (Photo courtesy of Stephen Simon/Moose Jaw Warriors)

Surrounded by other volunteers who knew Josh well, Sandra and Brad met fans, handed out bobble head dolls, and provided information about registering to become an organ donor.

Don Cherry knew all along that the hockey community would be a powerful ally in shining the spotlight on organ donation. "Folks, for some reason Canada is 23rd in the world for organ transplants¹, but I knew that hockey people could make a difference. For instance, when the defenseman of the Humboldt Broncos who was involved in that tragic bus accident donated his organs so others might live, organ transplant pledges tripled. God Bless him and his family. The Western Hockey League and other hockey organizations are working hard to make it a goal for Canada to rank in the top ten of countries for organ transplant."

1. Ranking in 2017





people currently waiting for a kidney transplant



Median wait time for a deceased donor kidney transplant

KRESCENT

Great Report Card for its First Decade

n 2005, The Kidney Research Scientist Core Education and National Training (KRESCENT) program was launched with the objectives of enhancing kidney research capacity in Canada and of fostering knowledge translation in health research.

Ten years later, now that over 50 trainees were awarded research grants, it was time to measure how well the program was achieving its intended goals.

To evaluate the impact of KRESCENT on its major objectives and on the careers of trainees after its first 10 years, an online survey of those who had completed or were enrolled in KRESCENT was conducted. Additional information was obtained from the trainees' curriculum vitæ and from a bibliometric analysis assessing scientific productivity, collaboration, and impact.

The results, which were announced in February 2017, were overwhelmingly positive:

- → 79% of KRESCENT trainees obtained grant funding from the Canadian Institutes of Health Research (CIHR)
- → 76% of KRESCENT Post-Doctoral Fellows received academic appointments at the Assistant Professor level within 8 months of completing training
- → 90% of respondents reported that KRESCENT had contributed significantly to their success in securing CIHR funding
- → 93% reported that KRESCENT had contributed significantly to the creation of knowledge

It's clear that the KRESCENT Program continues to foster kidney research career development and contributes to increased capacity, productivity, and collaboration.





2017 Medal for Research Excellence



Pictured (left to right): Dr. Brenda Hemmelgarn, Kidney Foundation National Executive Director Elizabeth Myles, Kidney Foundation National Immediate Past President Dr. Julian Midgley and Dr. Braden Manns

OR THE FIRST TIME IN THE HISTORY OF THE KIDNEY FOUNDATION OF CANADA, THE 2017 MEDAL FOR RESEARCH EXCELLENCE WAS PRESENTED TO TWO INDIVIDUALS.

Drs. Brenda Hemmelgarn and Braden Manns have been working together for many years and have demonstrated foresight and leadership that has had a major impact on patient priority setting and patientoriented research in Canada.

Drs. Hemmelgarn and Manns have had outstanding careers, highlighted by their mutual collaboration. Over the years, they have collaborated on more than 165 peer-reviewed publications and 30 research projects, including major research grants such as Can-SOLVE CKD, a recent Canadian Institutes of Health Research grant looking at patient-centered care in chronic kidney disease. Their collaboration has had a major impact on the translation of health care for patients with chronic kidney disease. Additionally, they both have been involved in different administrative roles related to the optimal delivery of renal services in the province of Alberta. They have been and are the principal organizers and innovators of a major renal epidemiologic centre, not only noted in Canada but throughout the world.



aunched in 2013, The Canadian National Transplant Research Program (CNTRP) is the world's only national research program worldwide that brings basic and clinical scientists in organ and tissue donation, solid organ transplantation and hematopoietic cell transplantation together with health economics, legal and ethics researchers, policy experts and knowledge users to overcome challenges to optimal use of donation and transplantation.

"Our achievements have culminated in our ability to showcase the success of the collaborations, the success of the network. the success of bringing patients and families in as partners in our research," says CNTRP Executive Director David Hartell. "We've succeeded in bringing the [research] community together in an integrated way, now what can we do with this? The next step is to think about things that were impossible five years ago."

The CNTRP is now poised to make a giant leap forward by adopting a new vision called the One Transplant for Life challenge, the goal of which is to fulfill every living and deceased donation opportunity and to turn transplantation into a cure.

Dr. Marie-Josée Hébert, CNTRP co-director with Dr. Lori West, explains: "Up to now, transplantation has been a treatment that allows people to have better life expectancies and quality of life, but it doesn't allow them to go back to a truly normal life. It's changing one chronic condition for another one that's easier to live with. We now have the opportunity to change this paradigm."

The Kidney Foundation is proud to be one of the Canadian Institutes of Health Research partners to support the CNTRP. Thanks in part to its recently-renewed funding, the CNTRP is ready to take on the challenge of working towards a global aim that would foresee transplantation as truly a cure.

Among the success stories that bring the fulfillment of CNTRP's new vision closer within its grasp includes the first successful human kidney transplant using a new ex vivo kidney device. In November 2017, a deceased donor kidney was preserved and kept healthy outside the body for three and a half hours in a device that mimics the body's physiological functions and was

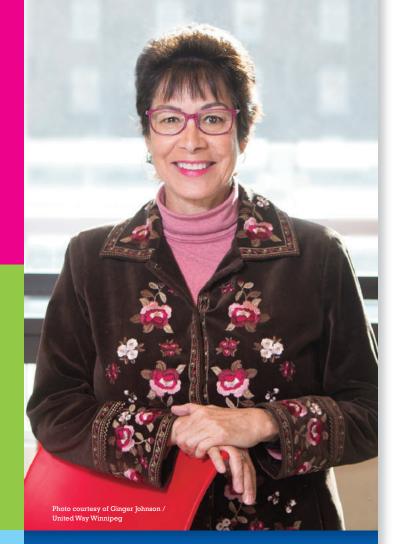
Dr. Marie-Josée Hébert & Dr. Mélanie Dieudé (Courtesy CNTRP)

successfully transplanted into a human, for the first time in North America. The technique uses a customized heart-lung bypass machine, with tubing adapted to the kidney's smaller blood vessels, and a specially blended preservation solution of blood, nutrients, minerals, amino acids, oxygen, glucose, antibiotics and drugs to help the kidney to "relax" and be in optimal condition prior to transplant. It was developed as part of a Phase 1 clinical trial at Toronto General Hospital, University Health Network, and part of the CNTRP Ex Vivo Organ Transplant Protection and Repair project, assessing the safety of the device, with subsequent phases examining its efficacy.

This technology has advantages over the usual cold storage method in which a deceased donor kidney is cooled on ice to about four degrees Celsius, with no oxygen, slowing down its metabolism, and inhibiting the repair process. The kidney cannot survive longer than 30 hours in cold preservation. The new warm preservation technique avoids the damage of cold storage and instead allows the donor organ to improve and repair itself, potentially leading to better outcomes for patients¹.



^{1.} https://www.cntrp.ca/single-post/2018/02/06/first-successful-human-kidnev-transplantusing-the-new-toronto-ex-vivo-kidney-device



HORIZONS 2022: The Future of Research

→ In May 2017, over 50 participants including patients, caregivers, researchers, health care providers, decision makers and funders, gathered for the HORIZONS 2022 workshop to discuss the future of the kidney research community in Canada. The workshop, organized by The Kidney Foundation of Canada in partnership with the Canadian Institutes of Health Research (CIHR) and the Canadian Society of Nephrology (CSN), featured wide-ranging, inclusive and energetic discussions.

The participants concluded that, while outcomes for people living with kidney disease have improved over the last five decades, the basic approaches to manage and treat kidney disease have not changed significantly. The focus remains mainly on management, control, and incremental enhancements. The group agreed to change how we work, so that we can start imagining a future without kidney disease.

The kidney community has the key elements for success already in place. Topmost among these are the three successful kidney research platforms inspired by previous HORIZONS meetings: The Kidney Research Scientist Core Education and National Training (KRESCENT) program, Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) and Canadian National Transplant Research Program (CNRTP), supported by the network built through The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET). However, these cores of excellence exist in a sea of fragmentation. The HORIZONS participants agreed unanimously that there is a need to bridge the remaining silos, and integrate incoherent data and systems in order to expand, strengthen, connect and create greater access to - and impact from - the three platforms already in place.

A final recommendation was the creation of a working group that will be tasked with continuing the conversation that was started at the workshop. The goal of the working group will be to create a Strategic Research Framework to fund and stimulate innovative research that will guide the Foundation's research activities for the next 5 years.

Personal Experiences Inform Research Priorities

athy Woods is using the lessons of her own journey with kidney disease to make a difference in the lives of others. In June 2015, she was introduced to Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD) when she was invited to attend a workshop. What she encountered was an initiative that has the ability and scope to help people with chronic kidney disease (CKD) and change the face of CKD by involving and including patients and their caregivers in this process.

Can-SOLVE CKD is one of five chronic disease networks established through the Canadian Institutes of Health Research's (CIHR) Strategy for Patient-Oriented Research (SPOR). The largest single investment in kidney research in Canadian history, \$12.5 million from CIHR was matched by more than \$24 million in grants, donations and partnerships secured by The Kidney Foundation of Canada, The Canadian Society of Nephrology and the researchers involved in the project.

A proud Anishinaabe woman originally from Northern Ontario, now residing in Winnipeg, Cathy was diagnosed with idiopathic membranous nephropathy in late 2010. It is a condition that occurs when the small blood vessels in the kidney, which filter wastes from the blood, become damaged and thickened. As a result, proteins leak from the damaged blood vessels into the urine and can lead to signs and symptoms known as nephrotic syndrome. People of indigenous ancestry have a higher risk of kidney disease than the general population.

"At my first visit with my renal specialist, I walked through the waiting room for those patients on dialysis and I was shocked," recalls Cathy. "A large percentage of them were of Indigenous descent. I could see myself in their faces."

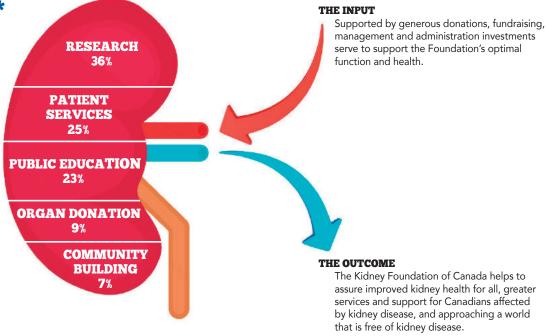
Today, Cathy is Co-chair of Can-SOLVE CKD's Patient Council and of its Indigenous Peoples' Engagement and Research Council. "It is my chance to give back to my community and to those who assisted me in dealing with my disease," notes Cathy. "I believe that the Can-SOLVE CKD network research projects can change the face of CKD for all by involving and including the patients and their caregivers in this process from the beginning."

"I'm proud the network is giving patients the confidence that their opinion is valid," Cathy continues. "The people who can do that are the researchers and nephrologists. Often they don't think to have patients in the room." The Can-SOLVE CKD project provides numerous volunteer opportunities for those directly impacted by chronic kidney disease.

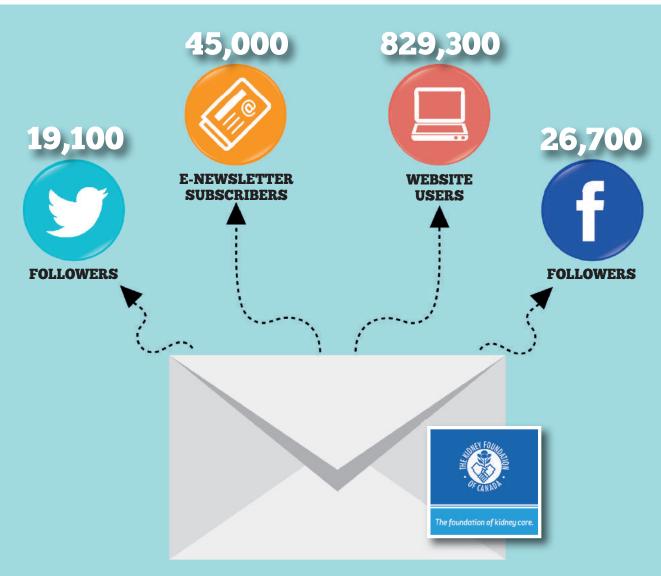




Spending by Program*



* Net of fundraising, management and administration costs



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