The foundation of kidney care.

THE KIDNEY FOUNDATION OF CANADA

2016 IMPACT REPORT

Hope | Support | Empowerment | Engagement

IMPROVING THE LIVES OF PEOPLE WITH KIDNEY DISEASE

TWITTER

14,923 followers

FACEBOOK

22,057 likes

NEWSLETTER

40,186 subscribers

1,187,014
website users

Public Benefit

The Kidney Foundation of Canada is people working together for a common cause. We are volunteers, individuals living with kidney disease, donors, and staff members — from all walks of life, all across Canada.

The Kidney Foundation of Canada exists for the enhancement of kidney health and the reduction and, if possible, the elimination of the burden of kidney diseases. The primary beneficiaries are people at risk of or affected by kidney disease.

The Kidney Foundation provides:

Hope

New knowledge and treatments generating hope will exist in the following areas:

- Knowledge of the kidney and kidney disease.
- Methods by which the new knowledge from research results can be translated into the treatment, prevention, and slowing of the progression of kidney disease.

Support

To achieve optimal health status, all people affected by kidney disease have access to healthcare and to wellness, socio-emotional, and financial support including:

- Equitable access to appropriate cost-effective treatment, as close to home as possible, regardless of background and personal circumstances.
- Timely access to successful long-term organ transplantation, if desired and appropriate.
- Comfort for those who withdraw from or do not wish dialysis treatment.

Empowerment

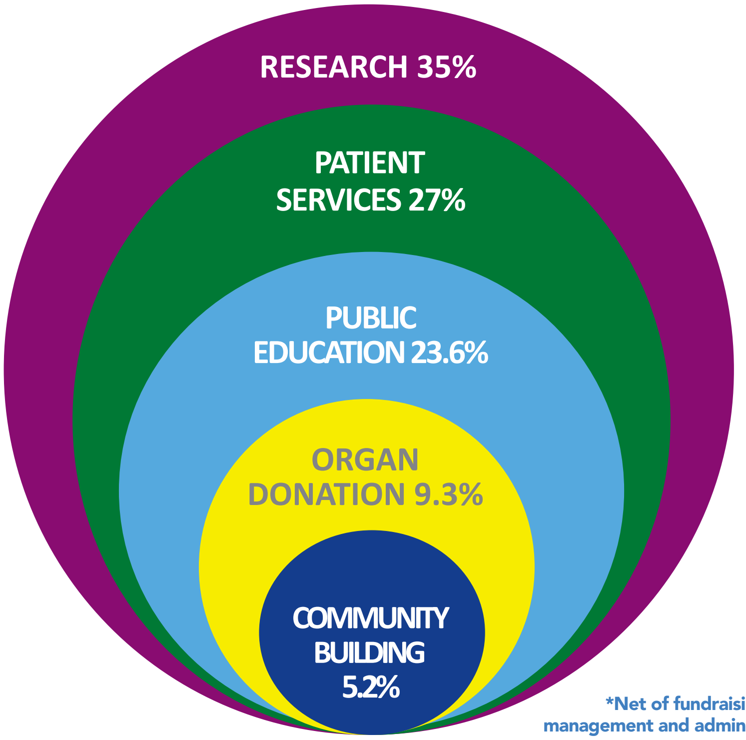
All people affected by kidney disease are empowered to maximize their outcomes:

- People have the knowledge to make effective choices to prevent, minimize, and seek treatment for kidney disease.
- People can advocate for themselves and others when navigating the system.
- The kidney community has a sense of belonging and a collective voice.

Engagement

- An informed Canadian public understands and responds to the impact of kidney disease.
- Effective provincial and federal policies and strategies exist for kidney research, kidney care, organ donation, and transplantation.

Spending by program*



*Net of fundraising costs, management and administration.

Message from the President and National Executive Director

One in 10 Canadians has kidney disease, and millions are at risk. The Kidney Foundation provides hope, support, engagement, and empowerment for people living with kidney disease, and makes a real impact on their health and lives.

We empower patients through education, improve treatment through ground-breaking research, and raise awareness about kidney disease by raising our voices and telling our stories.

One of the highlights of the year was the launch of Can-SOLVE CKD, an innovative multi-million dollar research network that has patients at the centre. The Kidney Foundation is a partner and has committed $3.8 million over five years.

We attended the Can-SOLVE CKD meeting in Halifax in May, along with researchers and patient partners working together, and the energy in that room was extraordinary. This is a group that is committed to transforming the way kidney disease is treated in Canada.

On World Kidney Day in March, The Kidney Foundation launched the completely revised edition of Living with Kidney Disease patient manual. The manual was split into two handbooks, one focusing on decreased kidney function and the other on kidney failure.

A diagnosis of kidney disease can be frightening, and raises a lot of questions. The manuals are distributed free to newly diagnosed people with kidney disease to help answer the many questions arise, and provide valuable information on managing the disease.

The new content and format has been getting extremely positive reviews from patients and healthcare providers alike. Over 19,000 handbooks were distributed in the first year.

To support advocacy efforts and increase awareness of kidney disease, we developed three patient story videos about living with kidney disease, one of them featuring Paul and his family. We also launched a new public service announcement featuring Canadian music icons Jann Arden, Russell Peters, and Paul Brandt, encouraging Canadians to register as organ donors.

None of this could have been done without the incredible staff and volunteers who are dedicated to improving the lives of people with kidney disease.

Whether it is 10-year-old Nash from British Columbia, Éric from Quebec, or Ken and his wife Carol from Alberta - whose stories are featured in this report - these individuals are taking control, raising awareness, and sharing their experiences to help others.

We are fortunate to acknowledge the nearly 20,000 volunteers who help us to do everything from convene committees and boards to organize community events and offer their shared experience as educators and awareness-builders.

Together, through our strong community and collaboration, we are building a better future for people with kidney disease.

Paul Kidston
National President

Elizabeth Myles

Elizabeth Myles
National Executive Director

BUILDING KIDNEY RESEARCH CAPACITY IN CANADA

Photo: KRESCENT fellowship recipient, Justin Chun

The Kidney Foundation has released *Impacts and Outcomes of Kidney Research in Canada.*

To read this supplemental impact report, visit the "Publications" section of our website.

The Kidney Foundation of Canada supports research into all aspects of kidney health, disease, and treatment. It has provided Canadian researchers with more than $115 million in grants since the start of the Foundation over 50 years ago. KRESCENT (Kidney Research Scientist Core Education and National Training Program) is a national partnership of The Kidney Foundation of Canada, the Canadian Society of Nephrology and the Canadian Institutes of Health Research Institute for Nutrition, Metabolism and Diabetes. The program aims to enhance kidney research capacity in Canada by supporting young researchers.

47 GRANTS

$3.07 MILLION *invested* **IN RESEARCH**

+

$8 MILLION *leveraged* **FROM OTHER FUNDERS**

Hope.

"KRESCENT is really instrumental for developing kidney research capacity in Canada." - *Heather Reich*

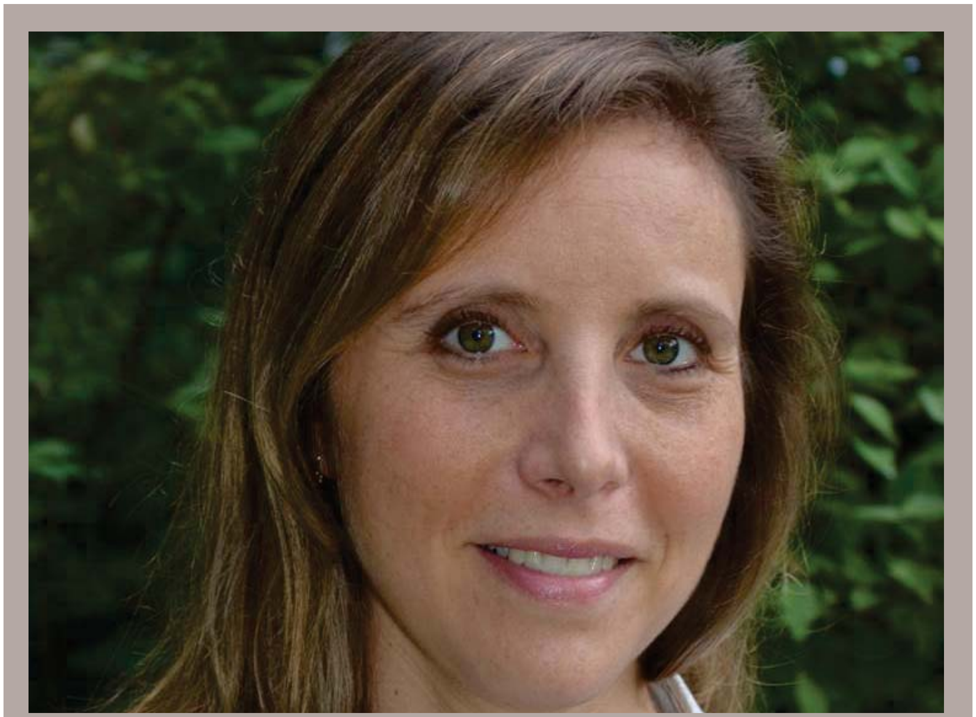
All things considered, Justin Chun might very well be your ideal young researcher. After a doctorate degree in Cell Biology at the University of Alberta and clinical training in nephrology at the University of Calgary, he decided to combine research training with medicine to better understand how to treat human disease.

Since very little was known about the causes of and treatment for kidney diseases, he chose nephrology. Today, this caring husband and father of two is pursuing a post-doctoral research fellowship in Boston at the Beth Israel Deaconess Medical Center and Harvard Medical School. Justin's post-doctoral fellowship is supported by KRESCENT.

In 2016, The Kidney Foundation provided funding to 20 KRESCENT researchers. Through the program, awardees receive salary support, as well as career development, mentorship and training.

Justin joined the laboratory of Dr. Martin Pollak to study how genetic mutations lead to kidney diseases such as focal segmental glomerulosclerosis. While working in a top-notch lab with amazing scientists, he never forgets why he is there:

"With very little to offer some of our patients with end stage kidney disease, I feel that my research may be able to help improve patient care in nephrology."



Dr. Heather Reich

Heather Reich received KRESCENT support both as a Post-Doctoral Fellow (2006-2009) and then as a New Investigator (2008-2011).

Today, she directs a translational research program at the University Health Network in Toronto. Her clinical work and research is improving outcomes of patients with glomerulonephritis.

Here is what she has to say about KRESCENT:

"KRESCENT was instrumental in providing the support to complete the extensive training required to develop a career in such a highly specialized area. The educational component was extremely helpful in teaching me fundamentals of research and study design, grant writing and the research review process.

Without KRESCENT I could never have developed a similar academic career. KRESCENT is instrumental for developing kidney research capacity in Canada. It is an unparalleled resource for both financial and educational support and has been effective in fostering a new generation of scientists focused on kidney disease research."

PROVIDING BUSINESS EXPERTISE TO RESEARCH COUNCIL

Photo: Ken Litchfield, patient partner with Can-SOLVE CKD

> Through its various research programs, including support for Can-SOLVE CKD, The Foundation's National Research Program has grown to become one of the most important sources of funding for scientists conducting kidney-related research.

The Kidney Foundation is a proud partner of the Can-SOLVE CKD initiative, which is a unique and innovative partnership of patients, researchers, healthcare providers, policy makers, industry and renal agencies that aims to create a powerful patient-oriented research network to transform the care of people affected by kidney disease.

This pan-Canadian initiative has the commitment of The Kidney Foundation, which is one of the largest funders, providing $3.35 million over five years. It benefits from the extensive support of the kidney community, with more than 35 patients participating in the various patient councils across Canada.

18

CAN-SOLVE CKD PROJECTS

35

PATIENT PARTNERS

Hope.

"It is a powerful feeling when research starts with those most affected."

- *Ken Litchfield*

Ken Litchfield isn't one to shrink from a challenge: this former project safety manager at Shell Canada has been fighting kidney disease since 2009.

It didn't stop him from climbing Mount Kilimanjaro and Mount Kenya in 2010 and from participating for the past two years in Kidney March – a 100 km walk through the foothills of Alberta, raising funds and awareness for kidney disease and organ donation.

Ken has been on dialysis since March 2016, anxiously waiting as his donors go through the screening process to donate a kidney.

"I am blessed beyond belief. I have 25 friends and family who have come forward as living donors. At the same time, I know my kidney disease is advancing. I also know the stats – some people die as they sit on the wait list."

Spring 2016 brought another turning point: just as Ken made the tough decision to step down from the job he loved, the Foundation celebrated a new Canadian research initiative: Can-SOLVE CKD, "Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease".

Featuring $40 million in funding, the project aims to improve kidney treatments and outcomes. Can-SOLVE CKD's founding principle is its engagement of people with chronic kidney disease and their families.

Ken Litchfield

Ken and his wife Carol immediately decided to get involved.

They provide their expertise to a 30-member national patient council – a group of Canadians of diverse ages and cultural backgrounds with first-hand experiences of kidney disease – and serve on the research project investigating how to increase living donor kidney transplantation.

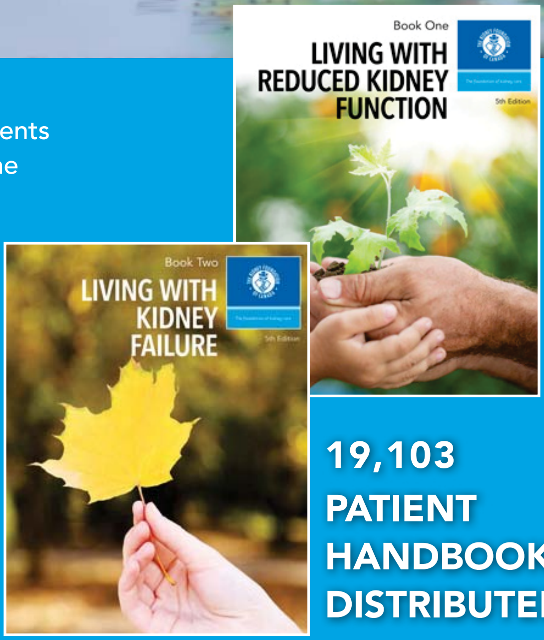
"It is a powerful feeling when research starts with those most affected," Ken says. "When we meet with the doctors, researchers, policy makers and kidney families, I see understanding – deep understanding – pass within our group."

PATIENT HANDBOOKS DELIVER SUPPORT AND EMPOWERMENT

Photo: Launch of the new patient handbooks

> Empowering patients with accurate and easy-to-understand information is important to a patient's wellbeing as they learn to cope with a chronic disease.

Providing support to kidney patients and their caregivers is core to The Kidney Foundation of Canada's mission. In 2016, The Kidney Foundation of Canada released a revised and redesigned fifth edition of its *Living with Kidney Disease* patient handbooks. Handbooks are provided free of charge by the Foundation to all newly-diagnosed patients across the country. Over 19,100 copies were distributed in 2016.



19,103 PATIENT HANDBOOKS DISTRIBUTED

Support.

"Feedback from Nephrology Social Workers across Canada is unanimous – The Kidney Foundation's manual is an invaluable resource for kidney patients and their families."

- Michelle Jensen, President,
Canadian Association of Nephrology Social Workers

The patient handbook has been a core service of The Kidney Foundation since 1993. This free resource has been an important source of information for Canadian kidney patients by helping them to understand what it means to be diagnosed with kidney disease and to help them navigate options so they are able to make informed choices about their treatment.

"The guide *Living with Kidney Disease* was a great help to understanding our children's illness and to prepare us to live with this new reality," says Silène Beauregard, the mother of Marcelline and Hadrien.

In 2016, the Foundation released a newly-revised and updated version of the patient handbooks. To better serve patients and help them with their kidney disease experience, the handbooks are now provided in two volumes: one offers information and resources to those living with reduced kidney function, while the other provides education about treatment choices to live well with kidney failure.

Silène Beauregard and Marcelline

Handbooks have been revised into 2 volumes to best meet the current needs of a patient

Book One, *Living with Reduced Kidney Function*, is intended for people whose primary care providers or nephrologists have identified kidney damage with either normal or reduced kidney function. It provides information on how kidneys work, and focuses on delaying the progression and preventing end-stage kidney disease through lifestyle choices such as diet, exercise and medication management.

Book Two, *Living with Kidney Failure*, is intended for patients who need more information about treatment options. It provides information on dialysis, transplant, and conservative care. It also covers advance care planning and practical matters such as working, finance and insurance.

Patients handbooks are typically distributed to patients through healthcare professionals working in renal units. Since 1993, when the patient information manuals became a core national program, it is estimated that the Foundation has distributed more than 100,000 of them across Canada.

HELPING PATIENTS MAKE INFORMED CHOICES ABOUT CKD

Photo: Maria Carnevale and Al Kimick share a laugh, as they often do during her dialysis

Educating is empowering. By keeping informed, patients and their families have the tools they need to help them manage their disease and minimize its impact.

Being diagnosed with chronic kidney disease (CKD) can be devastating for patients and their family. Reducing the burden imposed by CKD is a goal of The Kidney Foundation. Educating the public about prevention, available treatment options, and organ donation is key to raise public awareness about this serious health issue.

76,497

kidneycommunitykitchen.ca

users

131,740

EDUCATIONAL BROCHURES DISTRIBUTED

Support.

"Watch your food, watch what you drink, be patient and kidney disease won't be too scary for you." *- Maria Carnevale*

It was July 21, 1976. Even though that was more than 40 years ago, Maria Carnevale remembers her first day on dialysis like it was yesterday: two doctors sat on either side of her chair and held her hands as it started.

"I was so scared, I cried. I had never seen dialysis before. No one spoke Italian, so no one could explain it to me," she recalls.

In her second year of dealing with kidney disease, Maria received a kidney transplant and remembers taking 49 pills a day.

"My stomach has always been very strong. I am very careful with what I eat," she says. When her transplanted kidney failed, Maria was back onto dialysis within three months.

> **Patient experience shows renal care has come a long way in 40+ years**

Karen Bardi, who has known Maria for 40 years, remembers that era too – she was a renal nurse at Foothills Hospital in Calgary back then: "patients were horribly nauseous in the first hour of their dialysis. We've come a long way since then."

Treatment options and support mechanisms for those with kidney disease have improved considerably. The Kidney Foundation of Canada is proud to have contributed to those improvements by investing more than $115 million into life-changing research in the past five decades.

These days Maria takes three pills a day, noting that "everything is so much better than when I was first diagnosed."

Access to information about kidney disease and available treatments was also key in Maria's success in handling her 40-plus-year journey.

Doctors, nurses, chaplains and patients at the dialysis clinic she attends three times a week are like family, and she conscientiously follows the advice of her dieticians and the renal experts.

She makes sure to share gentle suggestions with those newly diagnosed: "Watch your food, watch what you drink, be patient and kidney disease won't be too scary for you."

The Kidney Foundation offers a variety of programs for patients, including subsidies for summer camp, short-term emergency financial assistance and Kidney Connect, an online portal to connect patients to others for shared experiences.

$171,000
IN CAMP
subsidies

1,178 MEMBERS
Rein-Réseau / Kidney Connect

$575,000
SHORT-TERM FINANCIAL ASSISTANCE DISTRIBUTED

BUILDING A STRONG AND UNITED KIDNEY COMMUNITY

Photo: The Kidney Kids Crew in action

When it comes to helping patients and families connect, community-driven activities are key.

The overwhelming burden of kidney disease is easier to bear when shared with other patients, families, caregivers and friends – people who know exactly what the family is going through. The Kidney Foundation of Canada provides different avenues, through events, programs and online forums, for people to connect and share information and experiences.

NEARLY 20,000 VOLUNTEERS across Canada

Engagement.

> **“I am so proud to be Nash’s Mom. He has turned something terrible into something amazing.”**
> *- Fallon Overton*

What’s striking when you look at pictures of Nash Overton is his smile. Nash is a 10-year-old boy who simply cannot stop smiling. In spite of all.

Nash was diagnosed with nephrotic syndrome when he was two and a half and since then has been going through heart-breaking situations a kid should not have to experience. And still, he smiles and encourages other kids living with kidney disease to “stay strong and stay positive.”

Through this entire journey with kidney disease, Nash and parents, Gerald and Fallon Overton, have felt pretty helpless. But they also felt an urge to take control and fight by deciding to raise awareness and money for research and organ donation.

They started Team Nash and joined the Kidney Walk in 2013. With the help of friends and family, Team Nash has been one of the top fundraising teams for the last two years in a row for British Columbia and has raised over $33,000.

No wonder Nash received the Provincial Youth Recognition Award presented by the BC and Yukon Branch of The Kidney Foundation.

In 2015, Nash decided to join the Kidney Kids Crew, a group of 12 very special children under age 14, who are impacted by kidney disease in some way. They are either identified as having a kidney health challenge, on dialysis or may be waiting for a transplant.

Kidney Kids member Nash, age 10

“Kidney Kids shows people that kidney disease effects kids too,” says Nash. During their performances at various events, Kidney Kids not only dance to the *Fight Song* by Rachel Platten, but they also take turns going to the microphone and saying a few words about their relationship with kidney disease or organ donation.

“It is really fun to hang out with other kids that have kidney disease and go through some of the same things that I have to go through.” Raising money and awareness has become something Nash is really proud to do. “I am so proud to be Nash’s Mom”, says Fallon Overton. “He has turned something terrible into something amazing, and we will always continue to bring people together to raise money to fight this terrible disease.”

Kids helping other kids living with kidney disease: that’s what the Kidney Kids Crew is all about.

PATIENT RAISES AWARENESS ABOUT ORGAN DONATION

Photo: Éric Chandonnet has been organizing Le Tour de rein since 2011

Year after year, The Kidney Foundation of Canada can count on involvement and creativity of the community to raise funds and awareness.

Many patients, relatives, caregivers want their voice to be heard. They want to tell their story as a way of educating the public about kidney disease and organ donation. Through social media sites and public events, The Kidney Foundation of Canada helps them share their experience, and raise funds and awareness.

15,000 walkers and volunteers raise

$2.8 million

111 WALK locations

Empowerment.

"I'm still alive thanks to the kidney I was given." - *Éric Chandonnet*

Éric Chandonnet is a bodyguard with Quebec's Ministry of Public Security. He is a strong, active and down-to-earth man.

In 2010, he incidentally found out that he was suffering from kidney disease. His world collapsed: he was terrified by the consequences the disease would have on his health, but was even more devastated by the impact it could have on his wife and two sons.

Dialysis began in 2010, along with the wait for a transplant. "I realized I had do something to spread awareness of the disease and boost organ donation."

In 2011, he created Le Tour de Rein, an event that gathers patients, families, health care providers and decision makers for an 80 km cycling tour. He immediately decided to give proceeds to The Kidney Foundation because of the active role it has in promoting organ donation.

To date, the event has raised $80,000 - $30,000 of which was collected during the 2016 tour. For Éric, the most important thing he has accomplished is reaching a large number of people who now join him in spreading the word about organ donation. "I'm still alive thanks to the kidney I was given," says Éric.

Le Tour de rein 2016

Éric got a kidney transplant in 2013. His donor is a father of nine, an acquaintance who, when he heard about Éric's disease, simply offered to give him one of his kidneys. Several other transplanted patients take part in Le Tour de Rein. For Éric, they are ambassadors who prove, year after year, that transplanted patients can be fit and lead an active life.

Each year, before starting the ride at 7:30 a.m., Éric puts things into perspective. He addresses the participants in a very personal way.

"Today, we are going to cycle for about 4-5 hours. We will sweat and struggle, but we will have fun. Tonight, we will go back home, happy and satisfied. During these same 4-5 hours, some kidney patients will be seated in a dialysis room, plugged to a machine that will clean their blood. Tonight, they will go home, drained and exhausted. In two days, they will have to start over. Again and again."

And then Le Tour de Rein begins, his participants spinning for the cause.

VIDEOS HIGHLIGHT REGISTRY AND PERSONAL EXPERIENCES

Photo: Jann Arden, who appeared in an organ donation public service announcement

Raising the profile of organ and tissue donation is high on the public awareness priority list. Each year, approximately 76% of those on the transplant wait list require a life-saving kidney transplant for optimal health and restored lifestyle.

During the 2016 Junos, The Kidney Foundation was able to partner for the Universal Music Junos Party. This provided a related opportunity to develop a public service announcement about organ and tissue donation.

Canadian entertainment icons Jann Arden, Paul Brandt and Russell Peters challenged Canadians to do something about the thousands of Canadians waiting for the life-saving gift of organ donation by registering their wishes.

76% OF 4,600 CANADIANS REQUIRING A TRANSPLANT NEED A KIDNEY

REGISTER. TELL SOMEONE.

Empowerment.

> **“As more people understand the challenges of this disease, we know hope is right around the corner.”**
>
> *- Sandra Kidston*

The Kidston family joined a national conversation to create increased awareness of polycystic kidney disease by participating in a video series about its impact.

Sandra Kidston and her family know the impact of polycystic kidney disease (PKD) after living through years of the illness impacting their family. The genetic disease can span multiple generations and, for Sandra, it has taken her father, her brother, and it recently led Sandra into transplant surgery.

For the Kidston family, it was natural to get involved with The Kidney Foundation when an opportunity arose to share their experiences with PKD with other Canadians.

“Polycystic kidney disease impacts patients, families, friends and community,” Sandra said on getting involved in the video campaign with her family. “No one can be expected to ride the waves of PKD alone. Each person living with PKD lives a different life and has a different insight. They need our support. As more people understand the challenges of this disease, we know hope is right around the corner. The Kidney Foundation supports research, patients and families. A cure is possible.”

Personally, through the videos, Sandra wants to have a positive impact on her own family by giving insight into life with PKD, especially for her son.

Creating awareness through sharing family experiences

Nationally, Sandra hopes the videos go beyond creating awareness and have a longer, lasting impact on the state of PKD in Canada.

“Awareness brings us closer to a cure. It also prevents tragedy. Research and education provide a prolonged healthy life by early detection of PKD. Research and public awareness is a huge partnership. Through these videos, I hope we will achieve support, that researchers will aim high, give us hope and cure this disease or at least help us to better control PKD symptoms.”

The Kidstons are joined in the awareness-building video series by two other families, the Kerrs from Ontario and the Laviolettes from Quebec.

Craig Kerr is one of five siblings, four of whom have PKD, which now effects three generations of the family. “We wanted to create some awareness of the disease, of the Foundation, as well as share our personal story,” said Kerr of his family’s participation in the campaign.

Craig hopes their involvement with the project will go further than build awareness.

“Awareness is one thing, but, it’s what people do with it. The next step is having people empowered to do something about it, to take the next step … To take advantage of some of the patient services that The Kidney Foundation supports and that are available to them. Creating awareness is great but it’s also important to be empowered and do something about it.”

PREVENTION, EDUCATION ARE VALUABLE TOOLS

Photo: A screening clinic

Screening clinics and education programs are key to help prevent kidney disease, especially among at-risk populations.

In addition to providing screening and much needed education, the SeeKD program has also been effective in helping the Foundation to establish relationships with many communities of at-risk populations. Strategies will be developed to deliver community outreach and awareness programs to assist individuals improve their knowledge of risk factors for kidney disease, know the early warning signs of reduced kidney function, and to develop enhanced self-advocacy strategies.

3,213
people screened

Engagement.

"No matter how tough some of these challenges are, I have never held a screening clinic that didn't give me hope." *- Carmen Berglund*

Why would a nurse voluntarily choose early mornings, long drives and occasional bad roads to screening clinics in remote areas in central and northern Saskatchewan?

Ask Carmen Berglund and she'll simply reply: "No matter how tough some of these challenges are, I have never held a screening clinic that didn't give me hope."

Carmen is a registered nurse with the Saskatoon Health Region. She's been working in the area of nephrology since 2005, and, being curious and always ready for another challenge, she's held many positions at the Kidney Health Program in Saskatoon: dialysis nurse, clinical educator for training dialysis nurses, kidney disease clinic nurse, etc. "I find people with chronic kidney disease to be very inspiring."

Carmen has been involved with The Kidney Foundation since 2011. She has participated in and has volunteered at a number of fundraisers including walks.

In addition, Carmen has been working tirelessly with the Foundation to offer screening clinics in urban, rural, and First Nations community settings across Saskatchewan, and to promote increased awareness of kidney disease at conferences, health fairs, and other community events.

Carmen Berglund

Communites most at risk of kidney disease top priority for SeeKD screening program

During screening clinics, Carmen can assess the level of risk people may have and provide appropriate education so they can better understand what the risks mean and how they can minimize the chances of having kidney damage.

Prevention and education are words that Carmen uses frequently.

"The work that The Kidney Foundation does is so crucial in raising awareness about how common and how serious kidney disease can be. When people are aware of their risks for developing kidney disease, they can either prevent it or get support in managing the disease so they don't end up needing dialysis or transplant."

2015-2016
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National Director-at-Large

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National Director-at-Large

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Elizabeth Myles

Branch Office
Contact Information

British Columbia & Yukon Branch
4940 Canada Way, Suite 200
Burnaby, BC V5G 4K6
604-736-9775 / 1-800-567-8112
Pia Schindler, Executive Director

Northern Alberta and The Territories Branch
202-11227 Jasper Avenue
Edmonton, AB T5K 0L5
780-451-6900/ 1-800-461-9063
Flavia Robles, Executive Director

Southern Alberta Branch
6007 1A Street SW
Calgary, AB T2H 0G5
403-255-6108 / 1-800-268-1177
Joyce Van Deurzen, Executive Director

Saskatchewan Branch
1-2217 Hanselman Court
Saskatoon, SK S7L 6A8
306-664-8588 / 1-888-664-8588
Joyce Van Deurzen, Executive Director

Manitoba Branch
Unit 1 - 452 Dovercourt Drive
Winnipeg, MB R3Y 1G4
204-989-0800 / 1-800-729-7176
Valerie Dunphy, Executive Director

Ontario Branch
1599 Hurontario Street, Suite 201
Mississauga, ON L5G 4S1
905-278-3003 / 1-800-387-4474
Jim O'Brien, Executive Director

Quebec Branch
2300 René-Lévesque Blvd. West
Montreal, QC H3H 2R5
514-938-4515 / 1-800-565-4515
Martin Munger, Executive Director

Atlantic Canada Branch
56 Avonlea Court, Suite 204
Fredericton, NB E3C 1N8
506-453-0533 / 1-877-453-0533
Trina Ralph, Executive Director

The foundation of kidney care.

NATIONAL OFFICE
310-5160 Decarie Blvd.
Montreal, QC H3X 2H9
514-369-4806
1-800-361-7494
www.kidney.ca

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