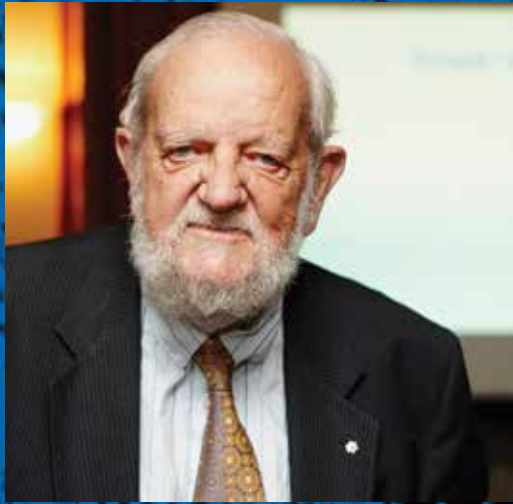


IMPACT REPORT 2014



The foundation of kidney care.

1964 **50** 2014
ANNIVERSARY

HOPE - SUPPORT - EMPOWERMENT - ENGAGEMENT

Hope - Support - Empowerment - Engagement

Celebrating our volunteer heritage

For 50 years, volunteers have been at the heart of The Kidney Foundation of Canada. From its founders in 1964 to the hundreds of thousands of people since then, passionate volunteers and supporters have made a positive difference in the lives of kidney patients and their families.

Throughout 2014, celebrations from coast to coast honoured philanthropic supporters and dedicated volunteers.



In 2014, The Kidney Foundation of Canada provided National Recognition Awards to many people across the country, and celebrated those who told their personal stories through 50 Kidney Stories, a national magazine celebrating The Kidney Foundation of Canada's 50th Anniversary. Among the award recipients were from left, Jarrett Osborne, his sons Harrison and Clark (back row), who along with Angie Osborne were recognized with a Public Awareness Award; and Dr. William Clark, who received the Harold W. Ashenmil Award. Other award recipients included Terry Leon, Jaya



Katawaroo, Alex Lifeson, Faye Clark, Simon Brodeur, Dorothy Roode, Gaétan Frigon, Hélène Héroux, The Nova Scotia Renal Program, Tracy Durkee-Jones, Sanjogta Bhandari, Phillip Chan, Don Cherry and Jason Kroft.

In addition to National Recognition Awards, many Kidney Foundation events celebrated the 50th Anniversary. Those closely connected to the Foundation and its start were reunited, including seated from left to right, Jack Boidman, son of The Kidney Foundation of Canada's Founding President Arthur Boidman; and founder Dr. John Dossetor; back row from left are Harold W. Ashenmil, one of the founders of The Kidney Foundation of Canada and National President from 1970-1974, and National Director of Development Linda Pellas, who joined them for a photo.

On our cover: Starting at the top left clockwise are Dr. John Dossetor, one of the founders of The Kidney Foundation of Canada; Liz and Victor Hanuse, kidney donor and recipient; Harold Ashenmil, Founder and Past President of The Kidney Foundation of Canada; Michel Perron, President of the Quebec Branch from 2002-2004; and kidney camp participant Penelope

The Kidney Foundation of Canada Past Presidents

2009 - 12: Kathryn Richardson, ON

2006 - 09: Niloufer Bhesania, ON

2004 - 06: Patrice Waché, QC

2001 - 04: Peter Davis, ON

1999 - 01: Mary Lou Karley, ON

1997 - 99: Marcia Bell, BC

1995 - 97: Owen B. Brown, NL

1993 - 95: Vivian Doyle-Kelly, QC

1991 - 93: Mary Catharine McDonnell, NS

1989 - 91: Neil Bronsch, AB

1988 - 89: Alfred Coll, ON

1986 - 88: Doris Norman, NB

1985 - 86: Kenneth R. Hughes, MB

1983 - 85: Howard McNutt, NS

1981 - 83: Barry S. Arbus, ON

1979 - 81: Stephen A. Stein, ON

1977 - 79: Ben Vanden Brink, AB

1976 - 77: David Ornstein, QC

1974 - 76: Roger P. Kerans, AB

1970 - 74: Harold Ashenmil, QC

1964 - 70: Arthur Boidman, QC

A Message from Our President



In my rounds as a pediatric nephrologist, I am constantly reminded of the harsh reality that chronic kidney disease changes lives forever. Its diagnosis instantly creates a lifelong commitment to treatments, ranging from dialysis to transplant, which is currently the best treatment option for severe chronic kidney disease. There is no cure.

For 50 years, The Kidney Foundation of Canada has made a positive difference in the lives of patients. Through its tremendous dedication to investment in research, treatment options have improved dramatically; we are getting closer to finding the causes of kidney disease and to discovering the ways to prevent it.

We strive to be innovative in finding new ways to deliver patient supports. Our quickly-expanding online patient support network, KidneyConnect.ca, and the online Kidney Community Kitchen, are popular tools for today's web-savvy audiences.

In 2014, we ramped up efforts to get Canadians to think about their kidney health and what it could mean to them. Our new online assessment tool saw over 5,800 people complete the quiz and learn more about their kidneys.

There was much to celebrate during our 50th anniversary. This was a year of reflection, a time to honour our founders – the family of the late Morty Tarder, and Dr. John Dossetor, whose collective vision for the eradication of kidney disease through research, along with the ongoing support of patients, is still central to today's mission.

It is also the time to renew our commitment to you, to those impacted by kidney disease and to those who choose to provide generous support through donations and endless volunteer hours. Together, we will continue to provide hope and support, to encourage patient empowerment and to engage Canadians in their kidney health.

Thank you for your ongoing support.

Dr. Julian Midgley, National President,
The Kidney Foundation of Canada



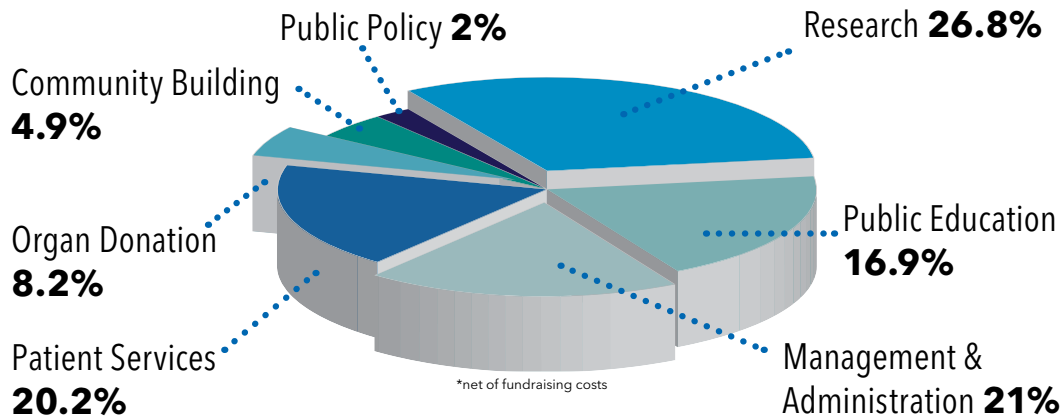
1964 - The Kidney Disease Foundation of Canada, as it was known then, was created by the family of the late Morty Tarder (pictured at left) with Dr. John Dossetor as one of its Founding Members.

3.3 105 RESEARCH
PROJECTS
SUPPORTED
MILLION

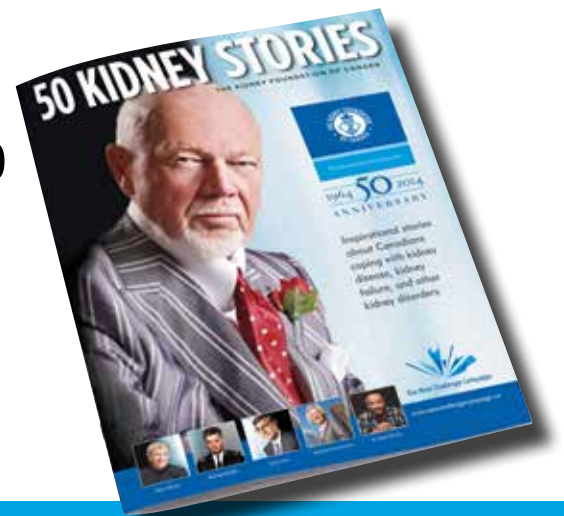
invested in research by The Kidney Foundation +
over \$3,000,000 more by partners

 **Krescent**
WORLD-CLASS TRAINING
PROGRAM **45** NEW
RESEARCH GRADUATES
SINCE 2005

79% Of Every Net Dollar Goes To Public Benefit*



**We distributed 24,500
50 Kidney Stories
magazines across
the country.**



1973 - The organization was funding medical research into kidney-related diseases by allocating \$25,000 for grants.

Hope

Patients given unique opportunity to help identify research priorities

Identifying priorities for health care research has traditionally not involved patients. However, with increasing focus on patient-centered care over the last few years, there has been a greater emphasis on better understanding patients and their needs when it comes to health care and research.

Dr. Brenda Hemmelgarn, a Nephrologist and Professor in the Departments of Medicine and Community Health Sciences at the University of Calgary, has been part of a collaborative and innovative patient-centered research project focusing on engaging patients with end-stage renal disease or those on dialysis in setting research priorities.

"We know that patients are the ones who live with the disease and are really 'the experts' in their condition and, because of this, it's important to involve them in the development of research questions," she said. "That's what this research is really all about."

To help guide the research, a Steering Committee was established comprised of patients, clinicians, caregivers, a Kidney Foundation senior staff lead, and researchers from across Canada. To help define the research priorities, a national survey was developed and distributed to kidney patients and health care providers. Over 1,800 research ideas were received and a shortlist of 30 priorities was identified. An in-person workshop of patients and renal professionals determined the top 10 research priorities.

"The research showed that patients want to be more engaged in their own care and decision making about their health options, and cited having access to their lab work and test results, or access to information about others' experiences to help foster better self management," said Dr. Hemmelgarn.



Dr. Hemmelgarn

IMPACT



"I was honoured to be asked to be part of this research project and responded yes almost immediately. I felt I could make a contribution, and that by sharing my perspective and experiences I might be able to do something for the betterment of all kidney patients."

Patient Participant Michael Gladish

In 1974 alone, the Foundation distributed more than a MILLION organ donor cards.

Hope

Transforming the study and care of patients through Can-Solve CKD

In August 2011, the Canadian Institutes of Health Research (CIHR) launched the Strategy for Patient-Oriented Research (SPOR). SPOR has five elements, including the creation of pan-Canadian research Networks. In October 2014, CIHR launched a funding opportunity that will provide support for the development and implementation of SPOR Networks in Chronic Disease. The Canadian kidney community has come together and has put in an application for this \$25 Million initiative, called Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD).

KFOC is a proud partner of the Can-SOLVE CKD. If successful in getting funding, the Can-SOLVE initiative will ensure: *By 2020, every Canadian with, or at high risk for, chronic kidney disease will receive the best recommended care, experience optimal outcomes and have the opportunity to participate in studies with novel therapies, regardless of age, sex/gender, location or ethnicity.*

IMPACT

- **Understand factors leading to renal and cardiovascular disease progression.**
- **Patients and those at risk receive the best recommended care options.**



2014 Medal for Research Excellence

Dr. Adeera Levin's research has focused on the early development of kidney disease and its association with

other conditions, particularly cardiovascular disease (CVD). Her description of unique abnormalities in the physiology of kidney patients with CVD, such as remarking the presence of anemia and abnormal levels of vitamin D, phosphate and parathyroid hormone (PTH), was novel and resulted in a series of basic research collaborations to better understand the biology of chronic kidney disease (CKD) and CVD.

As lead investigator of the Canadian Study of Prediction of Death, Dialysis and Interim Cardiovascular Events (CanPREDDICT) study, a large pan-Canadian project, she seeks to understand the factors leading to renal and cardiovascular disease progression in CKD patients. This new translational program, a first for nephrology in Canada, will study the genetic information (genotype) and observable characteristics (phenotype) of 2500 patients.

1996 - Launch of the Medal for Research Excellence. Dr. David Z. Levine is awarded the recognition during this inaugural year.

Support - Empowerment - Engagement

Short-term financial assistance comes at critical time



Rob Timpson with his cousin and kidney donor Ian Haugh

The Kidney Foundation of Canada provides nearly \$1 million in financial support to thousands of patients each year. With a diagnosis of kidney disease, many patients find themselves suddenly faced with the burden of trying to meet the additional – and often unexpected – financial requirements of such things as medication, supplemental health care supplies, and travel to and from dialysis.

“Prior to being diagnosed with this disease, I had no idea what it meant to be on dialysis. I started off learning how to do peritoneal dialysis, then peritoneal dialysis on a cyclor overnight, then doing hemodialysis at the hospital five days per week, and ultimately doing home hemodialysis. I had no idea that patients on dialysis had to sit for hours in uncomfortable chairs, basically at the mercy

of their renal failure. Days off were not an option as dialysis was necessary to maintain life. Throughout the process, I met many inspiring people – other patients, their family members, and the renal failure health care team members. My family and friends were a huge support to me, as well.

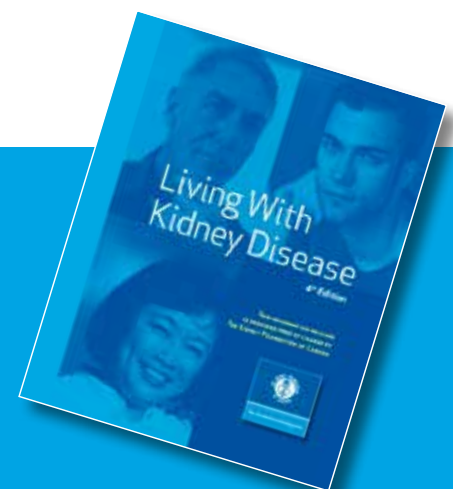
The Kidney Foundation is important to me, as it funds research into kidney disease and its prevention and management. On a practical basis, this organization provided me with funds to help offset the cost of hospital parking, and when I had to be in Ottawa for seven weeks to learn how to do hemodialysis at home, the Foundation provided some dollars to use towards accommodation and food.”

IMPACT

- **2,200 patients and kidney donors received short-term financial assistance.**
- **13,600 Living with Kidney Disease manuals distributed free of charge to patients.**
- **112,921 information brochures distributed.**

1993 - The Kidney Foundation Board endorses 3 core “national” programs, delivered to constituents across the country:

- Short-term Financial Assistance
- Living with Kidney Disease manual
- Information and Referral



Support - Empowerment - Engagement

Meaningful difference through partnership

Certain ethnic groups including First Nations and Aboriginal people are at greater risk for developing kidney disease.

The Kidney Foundation of Canada, Schnitzer Steel and the Automotive Recyclers Environmental Association (AREA) came together with a unique partnership to improve the kidney health and environment in First Nations and Aboriginal communities across British Columbia.

The partners will work with interested First Nations and Aboriginal community leaders to develop recycling programs for End-of-Life vehicles under the Recycle for Life™ program as well as using Schnitzer Steel's and AREA's expertise and environmentally approved processes to recycle other products. The end result is a healthier environment for people living in these communities.

First Nations and Aboriginal community leaders will also have the opportunity to ask the The Kidney Foundation to host a targeted screening event for their community members who are at high risk of developing chronic kidney disease. Early detection of chronic kidney disease provides people with the knowledge and information to make healthy choices that may delay or prevent the onset of kidney failure.

IMPACT

"Gilikas'la. We are happy to see this kind of partnership which will bring increased education and awareness about kidney disease to First Nations and Aboriginal peoples.

After our personal experience, we can't stress enough the importance of early detection of kidney disease, especially for First Nations and Aboriginal people who are at high risk."



- Liz and Victor Hanuse (Liz donated a kidney to her son Victor)

In 1965, The Women's Auxiliary of the Foundation organized the first child-testing program to screen for kidney disease.

Support - Empowerment - Engagement

Patients find connections through online portal



Hilary Heenan (at right), Kidney Connect moderator and Peer Support volunteer with her husband Mike and their daughter.

KidneyConnect.ca is an online social network hosted by The Kidney Foundation of Canada for people living with - and affected by - kidney disease. KidneyConnect.ca provides an online platform where members can create and share content and know they are not alone in their fight against kidney disease through blogs, forums, groups, chat and much more! KidneyConnect.ca complements the original Kidney Connect Peer Support program, which is offered through one-on-one telephone connections or group meetings.

IMPACT

- **800 members for online community.**
- **Patients find connections in ways which best suit their needs.**

"My experience with KidneyConnect.ca has been amazing! We are growing daily, which really contributes to the supportive atmosphere of our social network. A few key strokes, at your leisure in the comfort of your own home, and you are able to connect with hundreds of others who 'get it,' who share the same triumphs and struggles of living with kidney disease."

**2006 - Launch of KIDNEY CONNECT
Peer Support Program**



Support - Empowerment - Engagement

Kidney health for Manitoba's Filipino community



Jon Reyes, left, and his mentor Larry Vickar.

A Kidney Health Program is being developed for Manitoba's Filipino community.

Filipino people make up about four per cent of Manitoba's population, and are now recognized as Winnipeg's largest ethnic minority. While more than half a million people from the Philippines call Canada home, one in 10 call Winnipeg home!

Jon Reyes is a local Filipino business owner. He is a volunteer member of the Board of Directors for The Kidney Foundation in Manitoba. He is also the president of the Manitoba Filipino Business Council. Mr. Reyes led the way in this new direction.

"From The Kidney Foundation I have learned how significantly the Filipino population is impacted by chronic kidney disease," says Reyes. "In our community I have talked to many, many people who have family members and friends affected. I thought we needed to do something!"

The Filipino Steering Committee first started meeting in the summer of 2014 to discuss the need for awareness, education, and advocacy about kidney health. The committee aims to promote prevention strategies and build awareness of kidney disease. Volunteers meet regularly to determine priorities and plans for local projects, including a variety of communications tools to raise awareness of the importance of kidneys. Planning screening clinics is key to this new initiative.

IMPACT

- **\$200,000 investment in kidney health by CN.**
- **High risk communities top priority.**
- **Approximately 2,500 people screened across Canada.**

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.

Support - Empowerment - Engagement

Camps provide a respite from routine



B.C. Campers enjoy horseback riding.

Summer camp programs offer children and adults living with kidney disease a respite from their routines. The Kidney Foundation of Canada helps to fund camp experiences for patients in several provinces, including Quebec, British Columbia and Ontario.

With a wide variety of outdoor and sports experiences, trained support staff, and medical services on site at many locations, campers experience a wide range of activities across the country, from waterskiing to land-based activities like ziplining, archery and crafts.



Camps often get their start like the one in Quebec, the development of which was led by Dr. Marie-José Clermont. After starting her career in pediatrics, Dr. Clermont turned her attention to nephrology. It was after she participated in truly inspiring dialysis camps in New York State, she felt that children in Quebec deserved to benefit from the same experience, and so she decided to create a summer camp for young kidney patients in her home province.

IMPACT

"My favourite thing at camp is meeting new people and seeing old friends. Thank you for sponsoring me and letting me come to this wonderful place!" – Avneet

- **425 patients attended camp.**

In recognition of the International Year of the Child in 1979, the FOUNDATION HELD ITS FIRST DIALYSIS CAMP in the Okanagan Valley of Kelowna, B.C.

Support - Empowerment - Engagement

Kidney Pages make it easy to help



Thomas and his son Cohen.

Kidney Pages provide supporters with the tools they need to create an online fundraising page for The Kidney Foundation of Canada. Pages have been built in honour or memory of a loved one, to celebrate a transplant anniversary, wedding or birthday, and to support a fundraising event someone is hosting in their own community.

A variety of unique initiatives have been celebrated through Kidney Pages. Leah and Devon raised over \$24,000 in celebration of Leah's life-changing donation of a kidney to her mom. Young supporter July celebrated the 5th anniversary of her kidney transplant, from donor dad Bruce, by raising over \$12,300.

Supporters Eric and Charlene raised over \$3,400 to honour the memory of Charlene's late mother who had kidney disease and was on dialysis for over two years. They opted to connect fundraising to their climb of Mount Kilimanjaro to raise awareness and funds to ease the burden of kidney disease.

Thomas Dawson, with son Cohen, raised over \$2,300 to run the Grand Beach Sun Run in Manitoba. Thomas

is currently awaiting a kidney transplant and wanted to do something to help people with kidney failure. "I created the



page as an easy way for my friends, family and coworkers to support the cause that means the most to me and many others dealing with kidney disease," says Thomas.

IMPACT

- **\$150,000 raised since initiative started in 2012.**
- **185 people raised awareness of kidney disease.**

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.

60%

Support - Empowerment - Engagement

Walks bring kidney community together



Jason Hofer and his fiancée Amanda Hennessey, who met at the Kidney March.

Walks bring the kidney community together. Taking place across the country, kidney walks in their many forms provide patients, family members, friends and those from the renal professional community with a chance to come together to raise awareness and financial support for Kidney Foundation research, programs and services. Shared experiences create lasting friendships as people create one, strong kidney community across Canada.

"Kidney disease doesn't rule your life, if you don't let it," says Jason Hofer, who has participated in the 100 km, three-day Kidney March as both a crew member and participant since 2013.

In 2013, throughout the three days of Kidney March, he was impressed by the commitment

people he met along the way, including Amanda Hennessey. She was marching in memory of her mom, who she lost to kidney disease when she was only nine. Amanda was diagnosed with the same hereditary form of polycystic kidney disease in 2012. At the time, Jason was at the hospital dialyzing three times every week, and had been waiting for a kidney transplant for eight years

On December 10, Jason got the long awaited call that a kidney was available for him. The night before his transplant, he had one thing he needed to do. He asked Amanda to marry him. She said yes without hesitation.

IMPACT

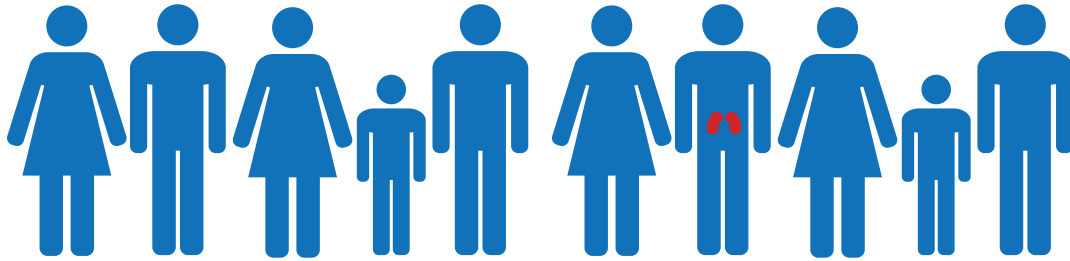
- **9,500 participants come together to raise awareness and funds.**
- **\$2.6 million raised to support Kidney Foundation research and programs.**



"I think it is important for people to give to The Kidney Foundation of Canada so they can help more families with medicine and doctors' appointments, and so they know about giving organs. This will help people not be sick anymore and help them live a longer life," says Simon, age 11, Honorary Kidney Walk Chair & Transplant Recipient

In 1979 March was officially declared Kidney Health Month in Canada and dedicated to increasing public awareness of kidney disease and raising funds for research.

The Kidney Foundation of Canada



1 in 10 Canadians has kidney disease and millions more are at risk.

25,000
Am I At Risk

brochures distributed.



Online self-evaluation
tool launched
www.kidney.ca/risk

Quizzes Completed: 5,876

Four languages: English,
French, Chinese, Punjabi



**2005 - "Am I at Risk" brochure distributed
through Branches and Chapters.**

2 new PSAs highlight risk factors

<https://youtu.be/rVb24fmEYsk>



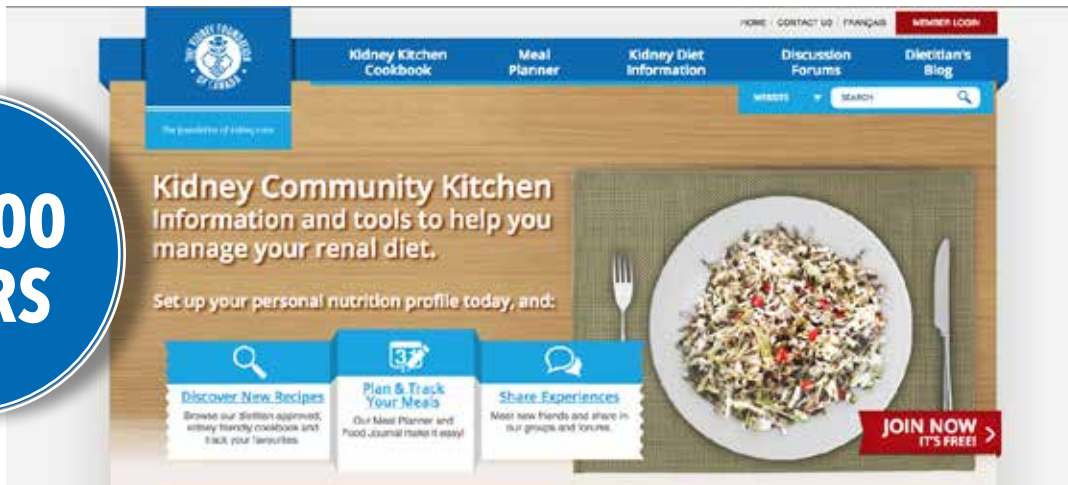
You Tube



<https://youtu.be/bxn-qsCIQDc>

KidneyCommunityKitchen.ca

**64,000
USERS**



8,300 Email Newsletter Subscribers



**Kidney.ca
2.7 MILLION
PAGE VIEWS**

6,425 followers



**11,000
Likes**



1996 - Kidney Foundation LAUNCHES ITS WEBSITE and within 2 years, the number of visitors is up to 11,000.

2013-2014 National Board of Directors

National President

Dr. Julian Midgley

National Immediate Past President:

Kathryn Richardson

National Treasurer:

Andrew MacRitchie

National Secretary:

Ken Mylrea

National Vice President:

Tetiana Gerych

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The Kidney Foundation of Canada's audited financial statements are available online at www.kidney.ca, in the publication section.