



**BRINGING  
PEOPLE TOGETHER  
IN A TIME OF NEED**



**2021 IMPACT REPORT**



***SPECIAL SUPPLEMENT INCLUDED  
IMPACTS & OUTCOMES  
OF KIDNEY RESEARCH  
IN CANADA***

## OUR VISION

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

## OUR MISSION

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

- Funding and stimulating innovative research for better prevention, treatments and a cure;
- Providing education and support to prevent kidney disease in those at risk and empower those with kidney disease to optimize their health status;
- Advocating for improved access to high quality health care;
- Increasing public awareness and commitment to advancing kidney health and organ donation.

### COVER:

Francine and Louise participate in a virtual peer support meeting.

PHOTO: RICHARD DUBOIS

### PHOTO ON RIGHT:

Eric Chandonnet, transplant recipient and Tour de rein organizer, with his wife, Nadine.

PHOTO: MARTIN ALARIE





**MESSAGE FROM  
THE PRESIDENT  
AND NATIONAL  
EXECUTIVE  
DIRECTOR**

In 2021, as we grappled with year two of ongoing lockdowns and restrictions due to COVID-19, it would have been easy to focus on what we have lost.

Dialysis and transplant communities were hit hard by the pandemic, which by the end of 2021 had overshadowed everyone's lives for 21 long months.

At The Kidney Foundation we strived to adapt and be nimble. In 2020, our in-person events and fundraisers, kidney camps and peer support groups were canceled but we persevered and continued many of them as virtual activities. Our research grants were paused for three months as research labs were closed across the country. We never gave up through all this and the Foundation emerged even stronger in 2021.

We transformed in-person programs to virtual opportunities, and we were committed to reaching just as many people, if not more, using digital platforms. Our virtual peer support program spread into rural and remote regions and engaged people who may not have been able to access face-to-face sessions previously. We held our first virtual educational forum; patient and caregiver input drove the content and topics. Requests for programming included topics to help them develop coping skills to manage their mental health and overall well-being during these unprecedented challenging times. Over 800 registrants participated in that forum.

Our regular educational webinars saw record registrations as well, and our updated Kidney Community Kitchen website, complete with a new meal planner tool, attracted 500-1,000 visitors per day. We held our first virtual Kidney Kids Camp, helping kids with kidney disease from across the country to know that they were not alone.

In 2021 we honoured all our research commitments including grants paused in 2020. We funded 31 new grants and raised over \$100,000 through our End Diabetic Kidney Disease (EDKD) campaign. The EDKD campaign will help to support an exciting new clinical trial that may transform the outcomes for people with Type 1 diabetes.

The Kidney Foundation of Canada has been Can-SOLVE CKD's most important partner since the network's inception, supporting the creation of new knowledge about kidney health and treatment options. We have pledged \$1.8M to continue our support and partnership in the anticipated next phase of the Can-SOLVE CKD research initiative, to support knowledge translation and implementation of learnings from 18 research projects into practice.

Throughout the pandemic, we have advocated to protect the patient population - those on dialysis and those who have or are waiting for a transplant. As an overall population, they are more vulnerable to complications of COVID-19. The safety and health of our community has always been top of mind and at the forefront of our decision making.

Our experiences with COVID-19 were fundamentally important to our organizational vision for the future. We wrapped up 2021 by developing a new 2022-2024 strategic plan. The plan focuses on four key priorities that are fundamental to our work: advocating for patient access to treatment, raising awareness of kidney disease to bring it out of the shadows as a serious health issue, ensuring the necessary funding to support programs, services, and research, and engaging volunteers to support life-changing work for all Canadians impacted by kidney disease.

We are incredibly grateful for those who have given generously to support the kidney community in a time of great need, from our dedicated volunteers, partners, staff, and board members to those who made financial gifts and participated in our events.

The passion of our kidney community, the resolve of our researchers, and the exceptional support of donors have been with us through thick and thin, and your dedication and support has fueled our work. For this, and all you do, we thank you!



**SYLVIE CHARBONNEAU**  
*National President*

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**ELIZABETH MYLES**  
*National Executive Director*

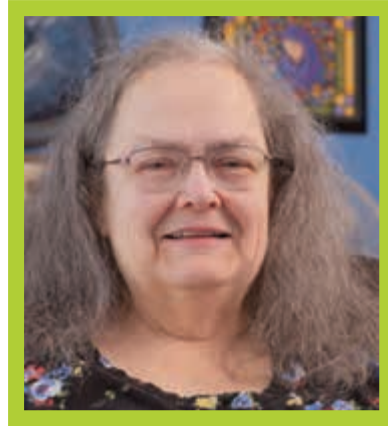
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## PEER SUPPORT: CREATING A COMMUNITY IN A TIME OF REAL NEED

For many people newly diagnosed with kidney disease, peer support is a truly indispensable resource for their emotional wellbeing. Additionally, it offers an opportunity for people living with kidney disease and caregivers, to interact and engage with peers who have experienced similar issues and questions as themselves.

As a core program for The Kidney Foundation, peer support has typically been available through in-person interactions in groups with a trained volunteer, or by phone one-on-one. After March 2020, with in-person activities cancelled, economic and job anxieties reaching an all-time high, and isolation impacting emotional wellbeing more than ever, the need for peer support grew significantly. Craig Lindsay, Senior Manager of Programs and Public Policy for the Ontario Branch, reported that those reaching out to peer support groups had more than doubled by 2021. Similar increases in demand for peer support services were felt throughout the country.

Like many other organizations, the lockdown required The Kidney Foundation to pivot peer support programs entirely to an online model.



Louise is a peer support participant.

In the first couple of weeks during the shift to virtual peer support groups, Craig worried that people wouldn't feel safe sharing delicate stories on web-based meeting platforms. Indeed, the transition to hosting support groups online happened so swiftly that staff and volunteers were essentially learning the technical ropes at the same time as those attending.

"Virtual formats for peer support allowed easier cooperation and sharing of resources and expertise from all branches of the Foundation," adds Craig.

Despite any initial worries, the transition to a virtual model presented numerous opportunities for connection. One of the most obvious benefits of the new approach is the sheer accessibility of it; people seeking peer support from around the country could simply turn on their computers and join from their living room, regardless of where they live, and it removed barriers to program access, like the cost of transportation to attend an in-person meeting.

With the increase in attendance came another opportunity for growth in the development of more niche groups to facilitate more

detailed conversation. A peer support group dedicated to parents of children living with kidney disease, for example, allowed those individuals to have space to pose questions specific to their concerns and the conversations in those spaces could become richer and deeper than ever before.

The format has also expanded the Foundation's opportunities to invite kidney health care specialists and other experts into the sessions to lead more structured discussions on specific topics. To give a better idea of how well-received this idea was, Craig noted that the group size increased nearly threefold when specialists started attending groups.

The new virtual support model also enabled new participants to bypass a kind of psychological fear of reaching out for support. According to Louise, a participant in peer support meetings, there have been many attendees during virtual support sessions who initially left their cameras off, only wanting to listen in. Gradually, they were able to gain enough confidence to participate in meetings and, in turn, share their own thoughts and questions.

The impact of peer support on the lives of those living with kidney disease and their caregivers is undeniable. "Peer groups supplied me with answers to questions I didn't even know I had," Louise said when recounting her own experience in seeking peer support after her diagnosis. For volunteers like Francine, who has been both a beneficiary of peer support and a volunteer group facilitator, the program has offered her a "sense of community."



Francine is a volunteer group facilitator.

For those who are new to peer support as well as those who were already members of the community, the virtual format has offered a profoundly innovative and inviting experience, one that will be integral to the program going forward. In reflecting on the past two years and thinking about the future of peer support to come, Craig notes that while the requests for in-person sessions are ramping up, virtual peer support will continue to be at the forefront of the program.

"As much as we often hear serious conversations and difficult questions posed in virtual groups, for the most part, there is a joyful and positive atmosphere in these created spaces. They share personal triumphs and celebrate accomplishments," acknowledges Craig. "They talk about family, work, and travelling. There is a lot of laughter too. I think that's one of the reasons we see so many people returning month after month, often to more than one group. They've created a community in a time of real need."

People with kidney disease and their caregivers can request **peer support services online** or by calling 1 866 390-PEER (7337).

## VOLUNTEERS TAKE TO THE AIRWAVES TO RAISE FUNDS

For nearly 25 years, The Chinese Renal Association has played a pivotal role in raising kidney health awareness. The volunteer-led chapter was started by patients and nurses who felt education, information and support needed to be more readily available to Chinese-speaking communities. Their many years of work resulted in a wealth of information and resources translated into the Chinese language. Many of these resources are available in the Kidney Health Resources section at kidney.ca.

People of Asian descent are at increased risk of developing kidney disease. Traditionally, the Association raises awareness through public kidney health education events, blood pressure clinics and fundraisers, but in 2021, the group took to the airwaves, hosting their first Chinese Radiothon on A1 Sing Tao Chinese Radio.

“A1 Sing Tao Radio, a national Chinese-language radio station that operates in Markham, Ontario, hosts numerous charity radiothons throughout the year to support a wide-variety of initiatives,” said Alan Hui, Chair of The Chinese Renal Association.

“But The Kidney Foundation’s radiothon was special, as we honoured the legacy of one of our founding members Benson Sy. Benson was a devoted member of the Chinese Renal Association, and he proposed the radiothon as a new way to raise funds and awareness in the Chinese community amidst the pandemic.”

While in the early days of planning, Benson passed away unexpectedly. His friends, family and fellow volunteers were committed to seeing the project through in his honour, never imagining that it would raise over \$124,000 in a single day to support The Kidney Foundation’s Short-Term Financial Assistance Program.

With a working group assembled, volunteers set out in uncharted territory. No one could have predicted the logistics needed to pull off an event of this magnitude. It started with developing a call to action and key messages, next was assembling a roster of guest speakers to fill 12 hours of on-air programming. “Sponsorship, marketing, setting up the call centre for donations, training volunteers... The list was long, but we did it!” said Alan.

“We were thrilled with the results” added Alan in conclusion, “We set out to raise awareness of kidney health and raise much-needed funds to support the kidney community. We accomplished both goals with our very dedicated group of volunteers, and numerous supporters.”



Members of the Radiothon working group with call centre volunteers on event day.

## KIDNEY CAMP FOR KIDS PROVIDED VIRTUAL FUN

For most kids, summer camp had been a distant memory since 2019 as the pandemic precluded programs from operating in 2020. Families expressed their understanding when it was announced that residential camps in most provinces would not return in 2021 either. But, there was also disappointment that there was not an opportunity for their children to get together and have fun with others who know what its like to face kidney disease at such a young age.

As has been done with so many other activities across Canada, the team at the Northern Alberta & The Territories Branch rolled up their sleeves and got to work on creating a virtual camp environment instead. A virtual program was designed to provide arts, physical activity, learning in a fun format for the whole family.

Led by previous camp participants and staff, this year’s virtual campers were able to have their siblings and other family members get involved in the activities. They participated in yoga, origami, hip-hop lessons, art projects, music, tent building (with their own couches and blankets!), growing plants, shirt tie-dyeing, a virtual fireside chat and more.

Leading up to the two-day online event, 345 kits were distributed to youth and their siblings across Canada so activities could be done at anytime. There were themes and suggested activities for each day leading up to and including the online sessions that were scheduled over two days; many supplies were provided in registration kits.

“Our online connections were filled with laughter and smiles,” said key organizer Flavia Robles, Executive Director at Northern Alberta & The Territories Branch. “It was great to see the artistic creations everyone came up with using their kits, and for us to be able to connect with families in this way.”

**“Thank you for your continued support! Kidney Camp for Kids was an amazing experience. The kids loved connecting with others. Thank you, Kidney Foundation, for the amazing opportunity to have my kids engaged and having fun.”**

Michelle (mom of a virtual Kidney Camper)



Jace paints stones with a kidney message.



Success with the origami instructions.



Julie shows the tie dye shirt she created.



## KIDNEY COMMUNITY KITCHEN INTRODUCES AN UPDATED MEAL PLANNER

**B**old and innovative change is not unfamiliar for The Kidney Foundation of Canada. In January 2020, we launched our new website, ushering in a new era of kidney awareness. Alongside our updated logo and website, The Kidney Foundation introduced a medley of new programs in order to continue offering unwavering support to those impacted by kidney disease.

Of those resources, the redesigned and improved Kidney Community Kitchen website, has already gone a long way in providing patients with invaluable recipes and tips on eating well. While being diagnosed with kidney disease necessitates a more conscientious approach to eating, that doesn't mean that cooking can't still be exciting and rewarding, which the Kitchen has largely demonstrated.

Now, adding on to the already invaluable resource of the Kitchen, The Kidney Foundation has introduced an improved meal planner, with some enhanced features.

The meal planner allows users to create and save daily and weekly meal plans. That sounds simple enough at first glance, but what makes the tool truly unique is its connection to the Canadian Nutrient File, a powerful database of ingredients. Whether users are looking to limit or achieve certain targets of sodium, potassium, protein, or phosphate – all very common with kidney disease diets – the meal planner calculates the nutritional content of recipes and ingredients, making it incredibly easy for users to understand the nutrients they're getting at a glance.



Chef Kris Gaudet hosts a cooking demo, one of the many enhancements made to [KidneyCommunityKitchen.ca](https://www.kidneycommunitykitchen.ca)

More than just making it easier to plan your meals day-to-day, the tool allows users to achieve their nutrient requirements, and also cut back on food waste, save on groceries by structuring meals to use all ingredients, and helps them to manage stress about what to eat every day.

[KidneyCommunityKitchen.ca](https://www.kidneycommunitykitchen.ca) has been receiving great praise, both from people affected by kidney disease and from subject matter experts. "In my research and preparatory work on the forthcoming program of International Federation of Kidney Foundations – World Kidney Alliance (IFKF-WKA) on Renal Nutrition, Diet and Recipes, I have found the Kidney Community Kitchen a most unique and practical website for patients, with excellent information and supporting tools," states

Dr. Siu-Fai Lui, President of the IFKF-WKA. "It is a very informative site for healthcare professionals."

As the meal planner is part of the Kidney Community Kitchen website, users browsing through recipes can select their favourite recipes and add them straight to their plan.

The meal planner is a living, breathing resource. According to June Martin, RD, CDE, a kidney dietitian of over 20 years, who helped support its development, new recipes are reviewed and contributed to the website regularly. Ms. Martin would know, as she is one of the dietitians who answers questions online and reviews user-submitted recipes.

She works alongside other dietitians, some of whom also contribute blog posts on a wide range of topics, including how to create a kidney-friendly charcuterie board and holiday cooking. One of Ms. Martin's recent blog posts, "*Meal Planning with the Kidney Community Kitchen*" is also fantastic reading material for newcomers to the meal planner.

## A CAMPAIGN TO END DIABETIC KIDNEY DISEASE

In 1921, one of the most important medical breakthroughs took place here in Canada. The research team of Dr. Frederick Banting and Dr. Charles Best discovered insulin. The breakthrough, which earned the researchers a Nobel prize in physiology or medicine in 1923, improved the lives of millions affected by diabetes. A disease that was once a death sentence could now be managed and treated.

“The discovery made by Dr. Banting and Dr. Best underscores the importance of research and how it has the potential to improve and revolutionize treatment options resulting in real, quantifiable change for those affected by a condition or disease,” says Dr. Leanne Stalker, National Director of Research at The Kidney Foundation.

To mark the centennial anniversary of this most celebrated medical discovery in Canadian history, the Canadian Institutes for Health Research (CIHR) Institute of Nutrition, Metabolism and Diabetes launched a large-scale strategic research initiative. 100 Years of Insulin: Accelerating Discoveries to Defeat Diabetes will see \$20 million invested by CIHR and its partners on several diabetes-related research projects.

### DIABETES AND KIDNEY DISEASE

Kidney disease and diabetes are closely linked. Diabetes is by far the leading cause of kidney failure. Morbidity, mortality, and the cost associated with the disease are significant concerns. Scientific and clinical

communities agree that there is much work to be done in improving diabetic kidney disease diagnosis and management as well as education to improve the awareness surrounding the connections of these two conditions.



Cindy didn't know her diabetes put her at greater risk of kidney failure.

The Kidney Foundation has committed a \$1 million investment over five years to fund a major diabetic kidney disease research project as part of the **100 Years of Insulin initiative**. CIHR will contribute an additional \$1 million over the same timeframe.

A rigorous competition was initiated to identify the research project that would be funded through this grant. “We’re pleased to be a funding partner for this important research initiative that leads the way for the next phase of Canadian discovery,” adds Dr. Stalker. The process included two rounds of peer review, which included participation from those with lived experience to ensure real-world pertinence.

Detailed information about the research project that earned funding can be found on pages R3-4 of the *Impacts & Outcomes of Kidney Research in Canada* supplement.

While the research competition was taking place, a campaign entitled **End Diabetic Kidney Disease** was launched to raise funds for this especially important initiative. Individuals whose lives have been deeply affected by diabetic kidney disease shared their stories to bring attention to this devastating and often overlooked disease.

Many people with diabetes, like Cindy, are not aware that they are at greater risk for kidney disease until they receive the diagnosis. “After my diagnosis, things went from bad to worse pretty quickly,” she recalls. “In just a few months, I was so swollen that I could barely move.” Dialysis treatments soon began, and she was placed on the waiting list for a transplant. The demanding dialysis treatments three times a week for four hours each time continued for three and a half years before she received news that her transplant would take place.

For Cindy and the countless others who are affected by diabetic kidney disease, The Kidney Foundation is committed to participating in important initiatives like this one in the hopes that it will lead to more scientific breakthroughs, improved patient outcomes and transformative change; looking towards a future where diabetes does not have to be the leading cause of kidney failure.

**CELEBRATING  
THE INAUGURAL  
2021 VIRTUAL  
FORUM**



A number of renal and allied health care professionals and those with lived experience gave their time to help us deliver an engaging virtual educational forum.

Even before the world was forced to pivot to doing things, The Kidney Foundation of Canada embraced the virtual landscape with its series of interactive webinars. Since then, digital meetings and conferences have become the norm, and the Foundation continues to spearhead new modalities of engaging with people living with kidney disease and caregivers.

In 2021, the Foundation held its first-ever Virtual Forum: a three-day online conference, featuring a variety of topics on living your best life with kidney disease, starting Tuesday, March 9 and concluding on World Kidney Day, Thursday, March 11.

The virtual medium allowed more attendees than ever to come together from across the country; patients, care partners, healthcare professionals, and researchers all over Canada could log in from their living room and join any of the 14 different sessions.

The 2021 Virtual Forum was innovative not only by virtue of its digital delivery method, but also for its patient-centric approach. Jan Clemis, a volunteer with The Kidney Foundation for over 25 years and a patient herself, was one of many people who helped organize and create the forum. Planning began back in November 2020, when volunteers met virtually to brainstorm topics and start mapping out the conference.

Jan was part of the group that created the sessions on self-advocacy, peer support, and virtual support; she was also one of the many volunteers who participated in hosting a panel discussion that she helped design. Working with a social worker to construct the sessions, she used her own experiences as a springboard for larger conversations.

“I was honoured that my voice was heard and used as a guiding point,” Jan remembers. “Living with kidney disease myself, I was able to address gaps by being involved in that planning process.”

According to Jan, highlights of the Virtual Forum were the broad range of topics and the holistic approach to wellness and living with kidney disease. Experts in their respective fields, from mental health to sexual wellness, were open and willing to talk about a wide scope of subjects, including the uncomfortable questions. There was no subject deemed taboo or off-limits, and this candor was spearheaded by patient volunteers.

Despite the fact that some people may find the virtual medium somewhat alienating, there were a variety of ways that attendees could get involved during the sessions. As the virtual sessions progressed, attendees started using the chat function, sharing email addresses and websites; during the more active sessions, attendees were encouraged to turn on their cameras and participate in the active break. Additionally, the networking session held on the last day of the conference provided unfiltered time for participants to connect with each other.

With the popularity of the inaugural Virtual Forum, it’s not surprising that presenters were soon hard at work planning their sessions for the 2022 edition of the Forum, which introduced a variety of new topics based on participant feedback and even more ways to engage with other attendees.

**WATCH THE  
VIRTUAL FORUM  
ON DEMAND AT**



**[kidney.ca/Virtual-forum-2021](https://kidney.ca/Virtual-forum-2021)**



## LIVED EXPERIENCE EXPERTS KEY TO RESEARCH SUCCESS

Every individual living with kidney disease takes a unique journey. The lessons they learn, the experiences they acquire, and the impact on their lives and those around them, provides a perspective that those who aren't affected and haven't lived it, cannot fully understand. It's for that reason that patient-oriented research, which involves a greater engagement of people living with kidney disease, has been prioritized in recent years.

"The Kidney Foundation of Canada research program is patient-priority-focused. Our research decisions are always made with patients top of mind," says Dr. Leanne Stalker, Director of Research at The Kidney Foundation. Recognizing that patients, caregivers, donors, and those directly affected by kidney disease, come to the table armed with their own expertise, has provided huge value to research programs. Learning to appreciate these individuals as experts and allowing their unique experience to help shape research training, improve projects, and ensure that research focuses on topics that are important to the community, provides value far beyond what anyone might have expected."

Research programs and patient-oriented research networks, such as The Kidney Foundation of Canada, Can-SOLVE CKD,

and The Canadian Donation and Transplantation Research Program are helping to bring patient-priority to the forefront of kidney disease and transplant research design. Organizations provide support and training to help patients become engaged and empowered in the research system and training for researchers on how they can integrate lived experience into their work and make research more accessible to the community.

"The need for a lived experience viewpoint has been recognized, and research programs have increased the importance of patient engagement in the process, as well as emphasizing focus on knowledge dissemination and communication to the community," says Dr. Stalker.

Lived experience partners provide invaluable insight at all phases of a research program. This includes helping to decide on program and funding focus including acting as peer reviewers, participating in individual study design, and contributing to research grants and publications. Their individual experiences are helping to shape the future of kidney research, from molecules and treatments, to addressing systemic barriers and cultural bias. Sometimes, a new perspective can spur a lot of change.



Mary shares her lived experience as a way to impact system change.

Nancy Verdin, and Mary Beaucage are two such lived experience experts who are actively involved in helping to shape and improve research funded by The Kidney Foundation.

As members of the KRESCENT (Kidney Research Scientist Core Education and National Training Program) patient council, Nancy and Mary play an active role in mentoring the next generation of kidney scientists and doctors on the importance of lived experience.

They met with us to recall their kidney disease journeys, their personal struggles, and the experiences that shaped their trajectory from patient to lived experience partner.

"It was the beginning of the 1988 Winter Olympic Games in Calgary," Nancy remembers. "I experienced a headache so awful, I thought I must be having a stroke." At the time, she had no idea her

kidneys were failing. She was taken to the hospital on Saturday night and began dialysis the following Monday.

Mary's experience was similar. In 2013, she began to feel unwell and attributed it to her diabetes. She went to the hospital, where she was discharged after her glucose tests came back within normal range. Mary's symptoms, however, progressed. The next morning, she lost fine motor skills and became unable to complete basic tasks. When Mary didn't show up for work, a concerned co-worker reached out and then called 911. By the time Mary arrived at the hospital the second time, she suffered a seizure, and was in a coma for four days. Dialysis was started immediately.

Nancy and Mary would join the ranks of a significant portion of kidney patients who get a crash course in what it means to have kidney failure. Nancy recalls a

complete lack of knowledge surrounding kidney disease. “Other than The Kidney Foundation of Canada information binder, there was such a lack of information to guide me”. Kidney disease can come with a steep learning curve.

They both recall how the attitudes of those around them, good and bad, shaped the journey. Barriers, such as locations, cultural differences, lack of knowledge, and long transplant wait times affected how difficult that journey would be. “Not everyone has the luxury of knowing people who know people,” Mary recounts. “It shouldn’t be like that.”

During that time, Mary remembers feeling compelled to act and thought: “As lofty as it sounds, if I can do anything to make a change (to the system) once I have this transplant I will. I just need to have the transplant. So, I did. That’s when everything else fell into place.”

Kidney disease catapulted Nancy into a new life direction. One in which she learned how to ask for help and to lean on those around her. “I know this sounds bizarre, but kidney disease took me in directions I never would have gone otherwise. It’s taught me to include people and it has kept me connected by needing help.”

As an occupational therapist, Nancy has always worked to make improvements for patients, even before she was diagnosed with kidney disease. Her involvement as



Nancy's engagement with researchers makes her feel her voice is valued.

a lived experience partner has made it possible for her to achieve that goal. A natural curiosity and an eagerness to learn have been valuable assets to her.

“Having the opportunity to support change throughout the system, from healthcare to patient care to creating wellness, recovery and a healing path for the patients themselves is very important to me,” says Mary. “And by healing, I mean holistically, beyond just our bloodwork.”

Both Nancy and Mary emphasized that their experience as a patient highlighted the importance of “having the opportunity to support change”. As such, they have both committed themselves to participate in being instruments of change for themselves, and those that will come after them, by actively participating in the kidney research landscape. The disease affected them. They are now committed to affecting the disease.

“I really like being involved with the KRESCENT trainees and hearing from them the things they’ve learned from me and from us,” offers Mary. “Its great feedback and we don’t always get that”

“It really has changed the perspective and awareness of new investigators,” adds Nancy. “It has been fun to watch how they have learned and grown with it. I love the discussions that go along with it.”

The inclusion of patient engagement and lived experience as an equal player in the research process is beginning to become normalized, but there is still a long way to go. “The system is continuing to improve, patients are being included earlier and being integrated in every phase of the research process” says Mary. Some pieces can only be explained or clarified by the patients themselves, and these perspectives have often been overlooked in research or clinical design.

“There are lots of things that are about the people, not just about the treatment,” Nancy states.

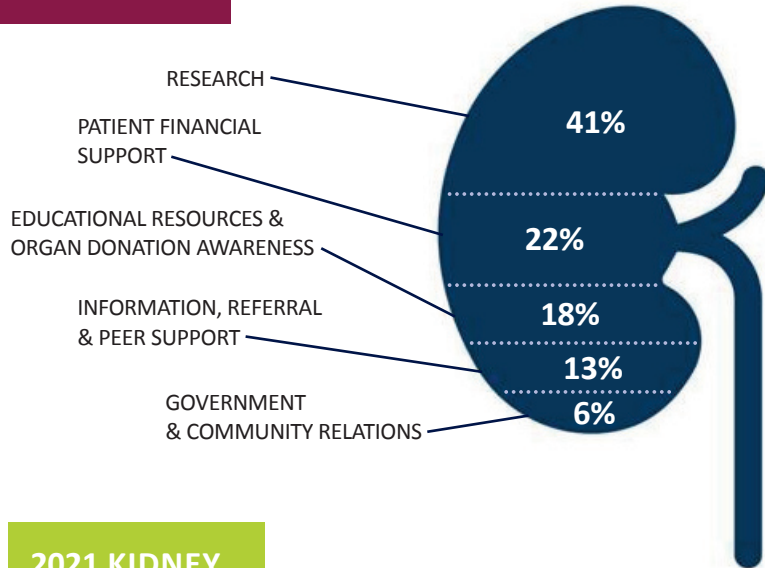
Mary and Nancy are both outgoing people who aren't afraid to dive into an unknown situation like becoming a lived experience partner. “Very often, it's people like us who are driven to create change and become volunteers,” notes Nancy. “But it's important for all voices to be heard and for a greater breadth of experience to be considered.”

Mary agrees: “I’m really big on mentoring other patient partners to get them comfortable and give them the tools that we may not have had when we started this. Because I think succession planning is really important, especially when we’re dealing with a disease like this where anything can happen.”

“As a life-long learner, with every study I sit on, I’m learning something new about kidney disease, about research, and about myself. I often come away energized and excited afterwards, because it’s been a constructive, productive, and useful meeting on a level playing field. What the patients have to say is valued,” concludes Nancy. “Feeling like we’re part of what is going on and that we are valued in the process, it fuels my need to support change and growth.”

## SPENDING BY PROGRAM

Thanks to generous donor support, The Kidney Foundation's program investments help to assure improved kidney health for all, greater supports and services for people impacted by kidney disease, and bring us closer to a cure.



## ONLINE ENGAGEMENT



**629,054** WEBSITE VIEWERS  
**2,700** WEBINAR VIEWS  
**91,100** SOCIAL MEDIA FOLLOWERS  
**57,181** NEWSLETTER SUBSCRIBERS

## KIDNEY FOUNDATION PROGRAMS



OVER **1,900** PEOPLE ACCESSED PEER SUPPORT  
 OVER **4,100** PEOPLE RECEIVED SHORT-TERM FINANCIAL ASSISTANCE  
 OVER **\$528,000** PROVIDED IN SHORT-TERM FINANCIAL ASSISTANCE

## 2021 KIDNEY WALKS



**106** VIRTUAL WALKS HELD INCLUDING KIDNEY MARCH  
 OVER **25,000** DONORS  
 OVER **2,700** PARTICIPANTS IN HUNDREDS OF COMMUNITIES

## ORGAN DONATION



**3,200** PEOPLE WAITING FOR A KIDNEY TRANSPLANT  
**3** YEARS, 9 MONTHS: MEDIAN WAIT TIME FOR A DECEASED DONOR KIDNEY TRANSPLANT

## EDUCATIONAL MATERIALS



**42,579** PATIENT HANDBOOKS DISTRIBUTED  
**27,145** EDUCATIONAL BROCHURES DISTRIBUTED



2021-2022

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[www.kidney.ca/about-us](http://www.kidney.ca/about-us)

[www.kidney.ca](http://www.kidney.ca)