



# 2021 Annual Report



**PKD FOUNDATION  
OF CANADA**



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# A Year in Review

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Like for all charitable organizations, 2021 was a challenging year for the PKD Foundation of Canada; due to the ever-present negative impact Covid-19 had on our abilities to connect in-person and fundraise in a public capacity. That said, thanks to the support of our donors and volunteers, the PKD Foundation of Canada was able to achieve a great deal of success, as we continued to pivot our programs, events and resources to a more accessible virtual platform.

Throughout the pandemic, the PKD Foundation of Canada positioned ourselves as a global leader in virtual educational engagement. By hosting four 2-hour stand-alone webinars, combined with our 3-day PKD Summit event (which consisted of nine hour-long presentations hosted by key stakeholders in the field of PKD), we were able to support thousands of PKD patients and their loved ones on their journey. Attendees were given the opportunity to ask questions throughout the educational sessions; giving them direct access to leading PKD professionals, whom they may not be able to connect with otherwise.

Health Canada once again recognized September 4th as PKD Awareness Day. In addition to their recognition, 41 cities and towns across Canada also followed suit with formal recognition. Furthermore, the PKD Foundation of Canada was able to secure a record number of monument lightings and flag raising ceremonies, in support of this important day! PKD Awareness Day is devoted to raising critical awareness of polycystic kidney disease, and the importance of discovering new treatment options and an eventual cure for those affected by PKD. Our social media efforts around this campaign are second to none, and help to shine a brighter spotlight on what it's like to live with disease, and how people can get involved in the fight to end PKD. .

# A Year in Review (cont.)

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Over the course of 2021, we expanded our working relationship with a vast number of like-minded patient support organizations across Canada, collaborating on a variety of educational resources. These included educational podcasts, joint webinars, cross-promotion of our respective resources and volunteer opportunities, and more. The PKD Foundation of Canada recognizes that we are stronger together, and that by working cohesively – we are able to provide patients, their caregivers and families, and friends with the greatest level of support possible.

As we continue to move through these challenging times with Covid-19, we extend our utmost gratitude and appreciation to our volunteers, donors and sponsors from all across Canada and beyond, for their unwavering support over the last year. Without these efforts, we would not have been able to expand our support services and fund the critical Canadian research that we did in 2021. We are not out of the woods yet with this pandemic, and we know tough times may lie ahead for 2022. However, with our dedicated leadership team and board of directors, combined with the invaluable support of our members, I know we will continue to make a positive impact on the lives of thousands of PKD patients across Canada and millions of patients on a global level.

I welcome you to take this opportunity to learn more about the PKD Foundation of Canada and what we accomplished this past year. We look to 2022 with great optimism, and welcome the chance to build off these successes achieved in 2021. Together, we will end PKD!

Respectfully,

Jeff Robertson  
Executive Director

# About the PKD Foundation of Canada



The PKD Foundation of Canada remains the only organization nationwide solely dedicated to raising awareness and funds for critical PKD research and patient education.

Since 2008, the PKD Foundation of Canada has grown from a provincial non-profit with one Chapter in Toronto, to a National non-profit charity that continues to expand all across Canada.

We currently have twelve (12) volunteer-driven Chapters, including Vancouver (BC), Edmonton (AB), Calgary (AB), Saskatoon (SK), Toronto (ON), York Region (ON), Hamilton (ON), Guelph (ON), Ottawa (ON), Montreal (QC), Halifax (NS) and Corner Brook (NL)



**PKD Foundation of Canada Chapters**

# Achievements

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## Fundraising

- Held the 3<sup>rd</sup> Annual Bike to the Moon fundraising event nationally; raising over \$50,000. Cyclists across Canada and beyond logged their KMs and raised funds while cycling in their local communities; with the goal of cycling the distance from Earth to the Moon!
- Hosted our signature fundraising event, the Walk to END PKD, virtually again this year with hundreds of participants taking part in the campaign from all across Canada; raising over \$149,000.
- Our DIY to END PKD campaign supported personal fundraising efforts of all shapes and sizes throughout the year, and allowed the event planners to get creative with their campaigns and fundraising goals.

## Programs and Services

- Hosted a variety of complimentary virtual education webinars throughout the year; covering a wide range of topics related to PKD.
- Hosted provincial social hours virtually, to keep connected with our members during the continued pandemic.
- Launched a new chapter in Winnipeg (MB); our first in the province.
- Developed new patient guidelines on a number of topics, including Diet Changes for Adults with PKD, Pain & PKD, Screening and testing for PKD, and Pregnancy & Family Planning with PKD.
- Hosted a 3-day virtual educational event, the PKD Summit; consisting of nine presentations on a variety of topics.

## Advocacy

- Received recognition from Health Canada to declare September 4<sup>th</sup> National PKD Awareness Day
- Secured 41 local proclamations from cities and towns all across Canada
- Had a record number of monuments and major attractions lit up teal and orange for PKD Awareness Day; including the CN Tower, the Calgary Tower and Niagara Falls.



# Our Guiding Principles

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## Mission

To promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.

As a leader in the field, the PKD Foundation of Canada contributes to this mission by:

- Funding critical Canadian research into treatments for PKD
- Developing educational and support resources for PKD patients and their loved ones
- Strengthening the visibility of the PKD community on a local and national level through Chapter initiatives
- Providing the PKD community with the tools and platforms needed to host various fundraising campaigns

## Vision

No one suffers the full effects of polycystic kidney disease.

## Governance

The PKD Foundation of Canada is a registered Canadian Charitable Organization (BN: 852683583 RR 0001)

The Board of Directors currently has five members, including a Chairperson / Treasurer, a Secretary, and three Directors. Board members each serve a three year term, and are appointed or elected at the Annual General Meeting.

# Voices of PKD

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## Meet Jennifer Morgan, Halifax NS

“On December 29th 2020, I went for what I thought was just a routine blood work check up. Our family had been on a waitlist to find a family doctor for a few years and we finally were matched. Our new doctor sent me for blood work while she waited to meet me. Five hours later, the local hospital called me and told me that I needed to come in right away – there was an emergency. I remember how scared I felt on that drive and because of Covid-19 restrictions, my husband wasn’t allowed to come in with me. The next few days were a whirlwind – so many tests and doctors, followed by an eventual diagnosis of PKD.

My life changed at that moment. They took me in for surgery to implant my chest lines to start dialysis immediately. I had no idea what to expect. Almost a year later and I’m so grateful to be doing well. They immediately started the testing process to get me on the transplant lists. We’ve recently learned that my husband and I matched in the kidney paired program, where he will donate one of his kidneys to someone in need, and another donor will give me their kidney. Our fingers are crossed!

Although I could focus on the negativity of my PKD diagnosis over this past year, instead I prefer to use that energy to be grateful for all we’ve learned and to remain positive, thankful and determined!

I’ve learned that I’m stronger than I thought. I do have strength within me when I need it the most, I just have to believe in it...and myself!





# Voices of PKD (cont.)

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“Our circle of family and friends has become much closer. I’ve learned how to reach out when I need some extra strength, support or just a mental break. I’ve learned how to ask for help! I’ve learned through all the extensive testing – that although I’m 46, I actually have the health of someone in their 20’s! So although I feel like the past year has aged me, I’m healthy!! I’m grateful for that!

We learned how to make healthy eating choices, even for our two kids. We’ve learned how nutrition impacts our overall health and what constitutes a healthy diet. We’ve all learned how to read the labels to make smart food choices. Also in this process, we have discovered some new delicious and healthy favourite recipes.

Our children are now being monitored. For me it was an emergency situation, but it won’t be for our two kids. We’ve learned that this early monitoring means they will have more options available, and this greatly helps relieve some of my guilt from unknowingly passing this on to them.

We are grateful for all the amazing improvements that have been made in treating PKD and we’ve been learning about the projects currently being explored; seriously life changing advancements!

Most of all we’ve learned just how grateful we all should be each day!”

- Jennifer Morgan



# Grant History



Year	Award	Researcher	Institution	Location	Project	Amount
1999	Grant	Dr. York Pei MD.	Toronto General Hospital	Toronto, ON	Genetic modifiers for progression of ADPKD	\$30K
2000	Grant	Dr. Marie Trudel, PhD.	Clinical Research Institute of Montreal	Montreal, QC	Molecular genetics of PKD1 gene	\$40K
2003	Grant	Dr. Zhen Chen, PhD.	University of Alberta	Edmonton, AB	Structure-function and regulation of polycystins and fibrocystins	\$32K
2007	Fellowship	Dr. Qiang Li, PhD.	University of Alberta	Edmonton, AB	Signaling and modulation of polycystin-2 by Rho GTPases	\$40K
2010	Grant	Dr York Pei, MD.	Toronto General Hospital	Toronto, ON	Patient registry database to enhance PKD research capacity	\$25K
2011	Grant	Dr. Marie Trudel, PhD.	Clinical Research Institute of Montreal	Montreal, QC	In vivo analysis of ADPKD pathologies for development of therapies	\$47.5K
2012	Grant	Dr. Marie Trudel, PhD.	Clinical Research Institute of Montreal	Montreal, QC	In vivo analysis of ADPKD pathologies for development of therapies	\$47.5K

# Grant History

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Year	Award	Researcher	Institution	Location	Project	Amount
2013	Fellowship	Dr. Moumita Barua	Toronto General Hospital	Toronto, ON	Translational Research Fellowship in HKD	\$35K
2014	Fellowship	Dr. Moumita Barua	Toronto General Hospital	Toronto, ON	Translational Research Fellowship in HKD	\$14.8K
2015	Fellowship	Dr. Ioan-Andrei Iliuta	Toronto General Hospital	Toronto, ON	Translational Research Fellowship in HKD	\$70K
2015	Fellowship	Dr. Almira Kurbegovic	Clinical Research Institute of Montreal	Montreal, QC	Translational Research Fellowship in PKD	\$41K
2016	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Refining Re-Purposed Drug Rx in ADPKD	\$43K
2016	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Genetic Modifiers of Polycystic Liver Disease	\$52K
2017	Fellowship	Dr. Ioan-Andrei Iliuta	Toronto General Hospital	Toronto, ON	Translational Research Fellowship in HKD (KRESCENT)	\$24K

# Grant History



Year	Award	Researcher	Institution	Location	Project	Amount
2017	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Year II Genetic Modifiers of Polycystic Liver Disease	\$52K
2017	Fellowship	Dr. Ioan-Andrei Iliuta	Toronto General Hospital	Toronto, ON	PKD / UHN KRESCENT Co-Fund	\$20K
2018	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Optimizing Metformin-based Therapeutics in ADPKD	\$40K
2018	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Funding support of PKD clinic	\$25K
2019	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Year II Optimizing Metformin-based Therapeutics in ADPKD	\$40K
2019	Grant	Dr. York Pei	Toronto General Hospital	Toronto, ON	Funding support of PKD clinic	\$37K
2020	Fellowship	Dr. Ioan-Andrei Iliuta	Toronto General Hospital	Toronto, ON	Research Fellowship (co-fund with UHN, Year 1)	\$32.5K
2021	Fellowship	Dr. Ioan-Andrei Iliuta	Toronto General Hospital	Toronto, ON	Research Fellowship (co-fund with UHN, Year 2)	\$32.5K

# 2021 Grant Recipient

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In 2021, the PKD Foundation of Canada awarded Dr. Andrei Iliuta a grant for the Year II of his Translational Research Fellowship at the Institute of Medical Sciences, University of Toronto. For this grant, the PKD Foundation of Canada proudly awarded Dr. Iliuta \$32,500, which was match-funded by the CIHR Can-Solve CKD SPOR grant.

Since 2017, Dr. Iliuta has been funded by the KRESCENT program and the PKD Foundation of Canada. His PhD thesis has focused on developing novel therapies to treat the metabolic reprogramming defect in ADPKD. Specifically, he has been conducting mouse studies to evaluate the effects of molecular mechanisms of intermittent fasting to treat autosomal dominant polycystic kidney disease (ADPKD). At the same time, he has been conducting a clinical study to better understand the pathophysiological mechanisms by which obesity (and its associated metabolic syndrome) accelerates the progression of ADPKD and a small pilot trial of intermittent fasting in PKD patients.



Institute of Medical Science  
**UNIVERSITY OF TORONTO**



# Advocacy & Awareness

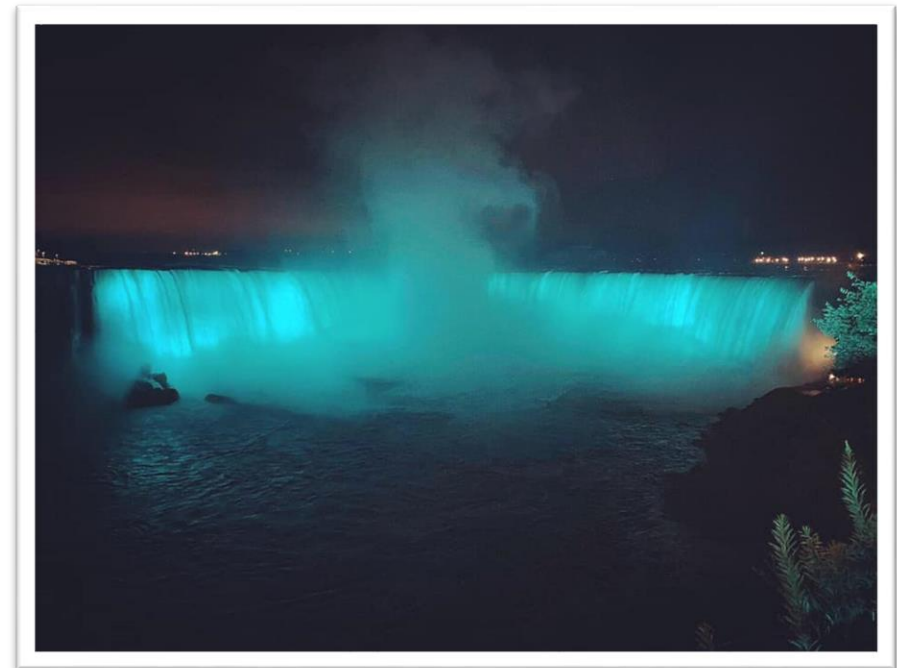


*The CN Tower (Toronto, ON) lit up teal for PKD Awareness Day*

## National PKD Awareness Day

This year, Health Canada once again recognized September 4<sup>th</sup> as National PKD Awareness Day – a special day devoted to raising awareness of this life-threatening, genetic disease.

We encouraged the PKD community to join in the conversation online. Thanks to a highly engaged social media and marketing campaign, the PKD Foundation of Canada achieved record-setting visibility online!



*Niagara Falls (Niagara Falls, ON) looking majestic in teal for PKD Awareness Day*



# Advocacy & Awareness (cont.)



In addition to Health Canada's recognition, the PKD Foundation of Canada also secured 41 local proclamations from cities and towns across Canada, and 15 flag raising ceremonies – where the END PKD flag flew proudly at various City / Town Hall.

This level of support and awareness from our community leaders was wonderful to see, and shows the PKD community that local municipalities are behind us in the fight to end PKD!



**Tom Mrakas**  
Aurora, ON



**Jeff Lehman**  
Barrie, ON



**Georges Bourelle**  
Beaconsfield, QC



**Rob Keffer**  
Bradford West  
Gwillimbury, ON



**Patrick Brown**  
Brampton, ON



**Doreen Assaad**  
Ville de Brossard, QC



**Naheed Nenshi**  
Calgary, AB



**Jim Parsons**  
Corner Brook, NL



**Terry Ungarian**  
County of  
Northern Lights, AB



**Alex Bottausci**  
Ville de Dollard-des-  
Ormeaux, QC



**Don Iveson**  
Edmonton, AB



**Margaret Quirk**  
Georgina, ON



**Mike Savage**  
Halifax, NS



**Bryan Paterson**  
Kingston ON



**Michel Gibson**  
Kirkland, QC



**Berry Vrbanovic**  
Kitchener, ON



Laval, QC



**Normand Marinacci**  
L'Île-Bizard - Sainte-Geneviève,  
QC



**Gordon Krantz**  
Milton, ON



**John Taylor**  
Newmarket, ON



**Brian Bigger**  
Sudbury, ON



**Doug McCallum**  
Surrey, BC



**Bill Mauro**  
Thunder Bay, ON



**John Tory**  
Toronto, ON



**Kennedy Stewart**  
Vancouver, BC



**Jim Diodati**  
Niagara Falls, ON



**Steve Clarke**  
Orillia, ON



**Jim Beis**  
Pierrefonds-Roxboro, QC



**John Belvedere**  
Ville de  
Pointe Claire, QC



**Sandra Masters**  
Regina, SK



**Jrizio Bevilacqua**  
Vaughan, ON



**Lisa Helps**  
Victoria, BC



**Giuliana Fumagalli**  
Villeray-Saint Michel-Parc  
Extension, QC



**Nina Bifulchi**  
Wasaga Beach, ON



**Frank Campion**  
Welland, ON



**Dave Barrow**  
Richmond Hill, ON



**Charlie Clark**  
Saskatoon, SK



**Alan DeSousa**  
Saint-Laurent, QC



**Michel Bissonnet**  
Saint Leonard, QC



**Danny Breen**  
St. John's, NL



**Don Mitchell**  
Whitby, ON

Thank you for your support!

# Advocacy & Awareness (cont.)

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## PKD Educational Webinars and the PKD Summit 2021

Throughout 2021, the PKD Foundation of Canada hosted four educational webinars on a variety of topics related to PKD. All of these 2-hour sessions were led by key stakeholders in the field of polycystic kidney disease. During these events, attendees had the opportunity to hear up-to-date information on how to manage one's diagnosis, as well as the latest findings in PKD research. All of these webinars were recorded and are now housed on [endPKD.ca](https://endPKD.ca), so people can watch them at their leisure.

We also hosted a 3-day virtual event, the PKD Summit 2021, which drew thousands of attendees from around the world! Each day consisted of three 1-hour presentations. Topics included:

- What's New in PKD Research
- Understanding Living Donor Kidney Transplantation
- Nutritional Management of PKD
- Managing Anxiety & Depression With a Chronic Disease
- The Current Landscape and Future Horizon For Children with ADPKD / ARPKD
- Pre-Implantation and Genetic Diagnosis & PKD



# Advocacy & Awareness (cont.)



## PKD Patient Vignettes and Maclean's Campaign

We introduced two patient vignette campaigns through our partnership with Maclean's, as a means of drawing attention to the realities faced by those living with PKD. These videos were designed to highlight the importance of PKD being better understood both in the medical community, but also in the general population as well.

By sharing one's PKD journey with us, we are able to show the world what it is like living with PKD on a daily basis, that there is hope for PKD patients, and most importantly – that they are not alone in their fight to end PKD.



*Jan baking with her daughter Bonnie and granddaughters, Harper and Cooper.*



# Fundraising



## 2021 Walk to END PKD: Campaign Results

Throughout the month of September, hundreds of PKD patients, family members and friends joined us again virtually for the PKD Foundation of Canada's signature fundraising event, the Walk to END PKD! \$149,000 was raised in 2021, with the campaign being considered a great success by all who participated.

The money raised from this year's virtual campaign allows us to continue funding critical Canadian research and fellowship funding, while also strengthening our mission to promote programs of research, education, support, awareness, and advocacy. It is because of the support of our generous donors and corporate sponsors that we are able to continue making a positive impact on the lives of those affected by PKD.

A huge thank you goes out to all of our incredible volunteer Chapter and Walk Coordinators, and their committees, our corporate and in-kind sponsors, and every single participant who walked to end PKD! We hope to be reunited in person for this campaign in 2022!



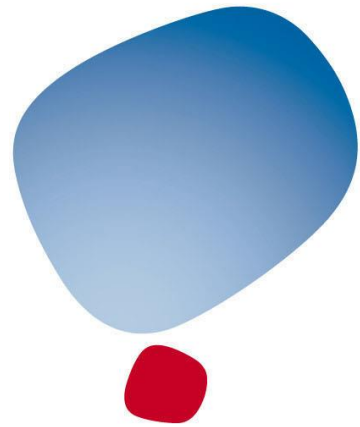
# Fundraising (cont.)

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## 2021 Walk to END PKD: Corporate Sponsorship

A very special thank you goes out to **Otsuka Canada Pharmaceutical Inc.**, who once again served as our **UNDERWRITING SPONSOR** in 2021; donating \$50,000 to the campaign!



Otsuka

# Fundraising (cont.)

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## The 2021 Bike to the Moon Campaign Reaches New Heights!

Over the course of June, cyclists from all across Canada and beyond took part in our Bike to the Moon fundraising campaign, raising \$50,000 for critical Canadian research and fellowship funding!

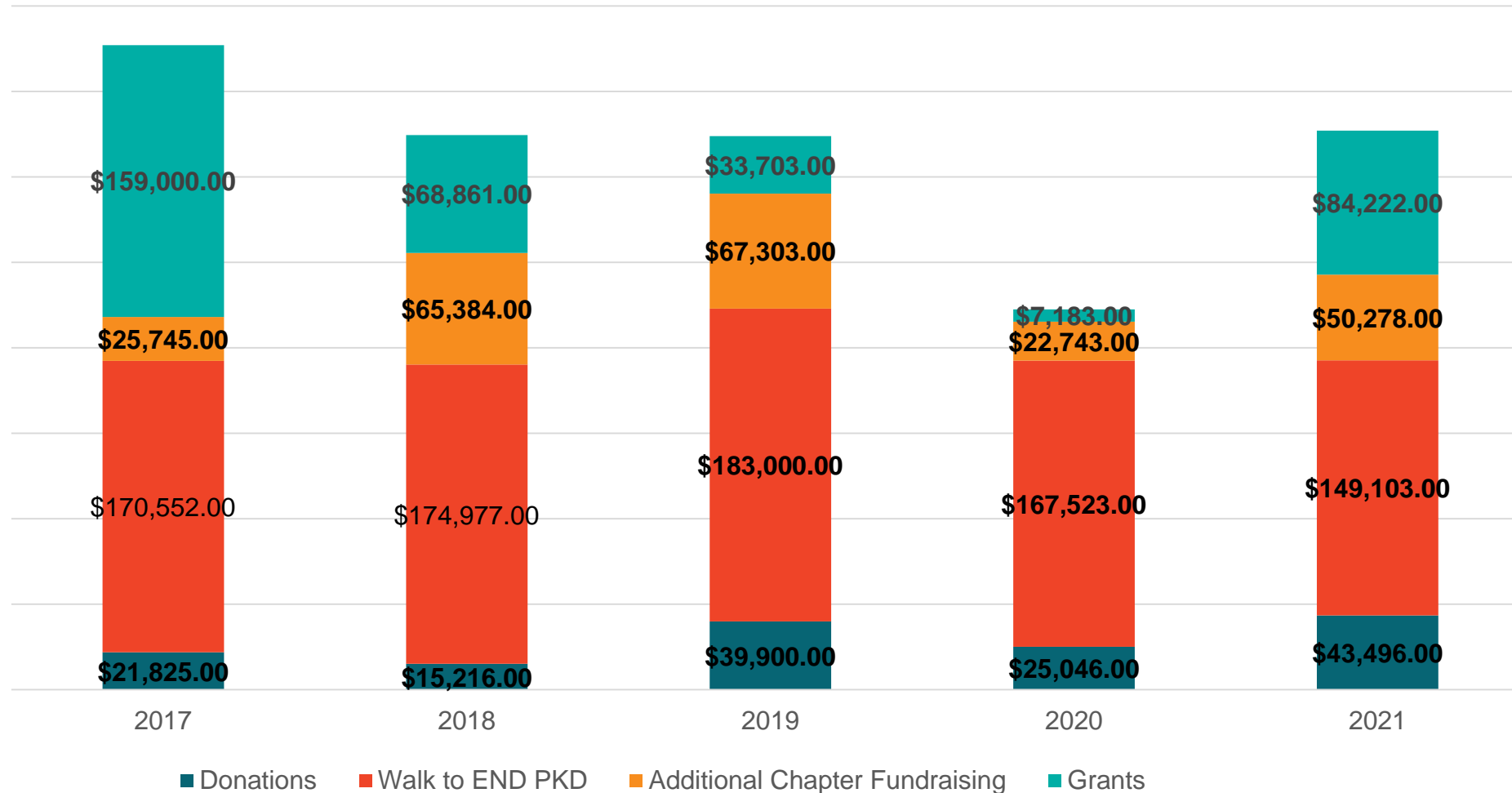
Bike to the Moon is an event that is perfect for both casual and serious cyclists. This year with consideration to local and provincial guidelines related to Covid-19, participants were able to choose any time between June 1-30 to complete their campaign. Some cyclists chose to ride solo, while others participated with friends and family members from their social bubbles.

We are so appreciative of all our cyclists this year, their supporters and donors, who helped to make this a record-setting Bike to the Moon campaign! We can't wait to continue our journey to the moon in 2022.



# Financial Reports

## Comparative Contributions

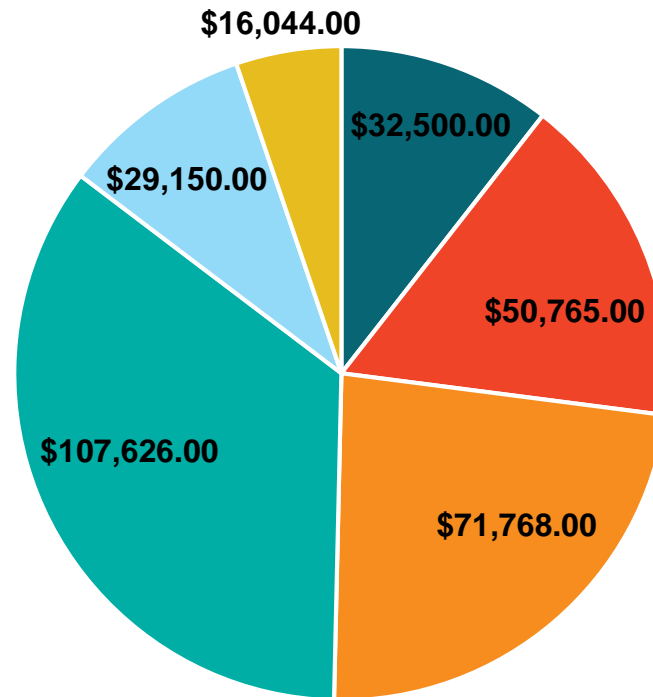


# Financial Reports (cont.)



## 2021 Expenses

*\*A total of \$136,281 (staff salaries, EI, and CPP) have been allocated into areas where staff time and attention has been focused.*



- PKD Research Grants
- Fundraising
- Foundation Growth / Development
- Member Services & Education
- Chapter Management
- Accounting, Legal & Insurance

# Our Team

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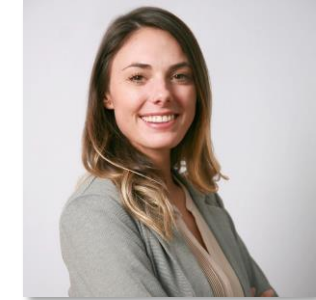
## **Executive Director: Jeffrey Robertson**

Jeffrey has been the Executive Director for the PKDFOC since July 2008. He is the driving force responsible for the success the Foundation has experienced over the past 11 years. Jeffrey serves as the lead role in the implementation of the Foundation's long-term strategic initiatives, and manages all day to day operations of the PKD Foundation of Canada.



## **Foundation Coordinator: Keara Johnson**

Keara is a seasoned volunteer within her community and is passionate about health, environmental, affordable housing and women's issues. She graduated with a bachelor's degree in geography from the University of Guelph and then went on to complete a post-graduate certificate in non-profit leadership and business management. Keara is excited to be a new member of the PKD community and is eager to join the fight to end PKD.



## **Chair / Treasurer: Doug Robertson**

Doug Robertson is a founding member of the PKD Foundation of Canada. His involvement with PKD began as a result of his wife Jan's diagnosis in 1980, at the age of 27. Since then, she has had two liver transplants and expects to receive a kidney transplant in the future. Doug and Jan have two adult children, Megan and Jeff.



# Our Team (cont.)

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## **Secretary: Dianne Hillier**

PKD runs in Dianne's family with both maternal grandparents and her mother having this disease. Over 17 years ago Dianne's father donated his kidney to her mother. Dianne and her family are excited to continue their support of the PKD Foundation of Canada, and remain dedicated to advocating for future treatment options that will improve the lives of those afflicted with PKD.



## **Director: Jarrett Osborne**

Jarrett Osborne's son, Harrison, was born with PKD ironically on World Kidney Day. His wife Angie, and their other two children, Clark and Madelynne, have dedicated their creative passions, entrepreneurial and philanthropic spirits to fight PKD and further support research, education, advocacy, support and awareness. Jarrett believes Harrison is the best thing that could have happened to his family and they are exponentially better because of him. They are indebted to him and will by any means, continue to fight and forge for a cure for PKD.



# Our Team (cont.)

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## **Director: Sara Hillier**

Sara Hillier has been involved in the PKD community with the PKDFOC for many years. Her grandmother had PKD and her mom also has this disease. It has affected all of her family's lives. Her grandmother fought PKD with all of her might, and now her mother is doing the very same! Sara is excited to be a part of the Board of Directors, and looks forward to advocating and fundraising for advancements in treatment options. It is her hope to one day see a cure for PKD.



## **Director: Stephanie Vardzel**

Stephanie is a passionate supporter of the PKD Foundation of Canada. She has dedicated herself to the Foundation in memory of her daughter Abigail, who passed away due to ARPKD in infancy. She is honored to bring her organizational and life skills, Master's education and drive to the organization. Stephanie and her husband are dedicated to finding a cure, so no other parent has to endure the heartache that they experienced.





**Thank You!**



**PKD FOUNDATION**  
OF CANADA