

The PKD Foundation of Canada

2012 Annual Report



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From the Chairman

Dear Friends,

With your continued support, 2012 has been yet another record breaking year for the Polycystic Kidney Disease Foundation of Canada! It is often difficult to look back on a year where so much has been accomplished and highlight only a few key achievements. In this spirit, I will look across what I see as our three main objectives:

1. Increase our contributions to primary research and one day find a cure for PKD
2. Expand our support and outreach to those afflicted with PKD and their families
3. Ensure more Canadians know what PKD is and how we can help

I am happy to say that with the dedication of our volunteers and Executive Director, we have continued to progress in all of these areas. Our Chapters have increased their attendance at events, we have maintained a high level of research funding (due to record breaking fundraising!) and we have had some great PKD exposure in the media! I encourage you to read the pages of this report with these three main goals in mind.

If you take away only one thing from this report, it is that you, your friends, families and co-workers are making a difference for all those affected with PKD. On behalf of the Board of Directors, myself and my family, I thank you all and look forward to another great year in 2013!

With heartfelt thanks,

Michael Kenigsberg
Chairman of the Board of Directors, PKD Foundation of Canada

From the Executive Director

What an exciting year 2012 was for the PKDFOC! As we say ‘goodbye’ to our first full calendar year operating as the newly rebranded *PKD Foundation of Canada*, positive growth of our front-line missions (strengthening programs of research, advocacy, education, support and awareness) is clearly evident.

In 2012, we launched our very first west coast Chapter of the PKDFOC; based out of Vancouver and serving the Lower BC regions. Appreciating the need for more Chapters in cities and provinces Without this type of support, it is encouraging to see members of the PKD Community stepping up and taking on these leadership roles for the betterment of PKD awareness and advocacy on a local level.



We also supported the second year of Dr. Marie Trudel’s 2011 Grant Award. With this being the largest grant awarded in the history of the PKDFOC, we look forward to providing you with a research summary in the coming months; outlining the work done to further advance clinical treatment of PKD by Dr. Trudel at the Clinical Research Institute of Montreal.

Additionally, we once again saw tremendous growth in our signature fundraising campaign – the Walk for PKD! With record setting attendances, corporate sponsorship and media support, our campaign generated an impressive 35% increase in funds raised from 2011. Because of this support and commitment from our donors, the PKDFOC will be able to continue funding world-class research into a treatment and eventual cure for polycystic kidney disease.

I embrace the new year with a warm heart and open arms. Together, we will collectively made an even bigger impact in PKD advocacy come 2013. Together, we will continue the fight to END PKD!

Working for a cure,

Jeff Robertson
Executive Director, PKD Foundation of Canada

The Organization

Polycystic Kidney Disease Foundation of Canada

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Mission Statement

The PKD Foundation of Canada is to promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for PKD; and to improve the lives of all that PKD affects.

Vision

No one suffers the full effects of PKD.

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, a Secretary and a Treasurer and two Directors. Board Members each serve a three year term and are appointed or elected at the Annual General Meeting.

Board of Directors and Staff

Chairman

Michael Kenigsberg is a Management Consultant at a global firm who has been a member of the Board of Directors since 2010. He has been raising funds for PKD research for over a decade. Prior to his role as Chairman, Michael consulted with the board on the direction of the charity.



Secretary

Doug Robertson is a senior manager in the consumer packaged goods industry, and has served as a board member of the PKDFOC since 1994. He is a past chairman of the Board of Directors. Doug resides in Richmond Hill, Ontario with his wife Jan and is a founding member of the PKD Foundation of Canada since 1994.



Treasurer

James Baird joined the Board as Treasurer in August of 2011. James currently works in business development for a global financial services firm, focusing on the development of strategic growth plans. He earned his Masters of Business Administration from the Richard Ivey School of Business at Western University, and is a CFA Charterholder.



Board of Directors and Staff

Director

Joseph Brant was born and raised in Toronto, ON with strong ties to both of his parent's reservations, Tyendinaga Mohawk Territory and Wikwemikong Unceded Indian Reservation. He is currently the President of Mohawk Foods Inc. Prior to Joseph's role on the Board of Directors, he was the volunteer Toronto Chapter Coordinator from 2009 onward.



Director

Michael Campbell joined the Board of Directors in January 2012. He has worked in the University Health Network Bioethics Program as a Senior Fellow in Organ Donation and Transplantation Ethics. He completed a Masters of Health Science degree and a Bioethics Fellowship at the University of Toronto Joint Centre for Bioethics. His research interests included ethical issues in the selection of living organ donors and the allocation of organs from anonymous living donors.



Executive Director

Jeff Robertson has been the Executive Director of the PKDFOC since July 2008. He is the Foundation's sole staff member, and the driving force responsible for the success the Foundation has enjoyed over the past four years. Jeff plays the lead role in the implementation of the Foundation's long-term strategic initiatives, and manages all day to day operations of the PKDFOC.



PKDFOC Grant History

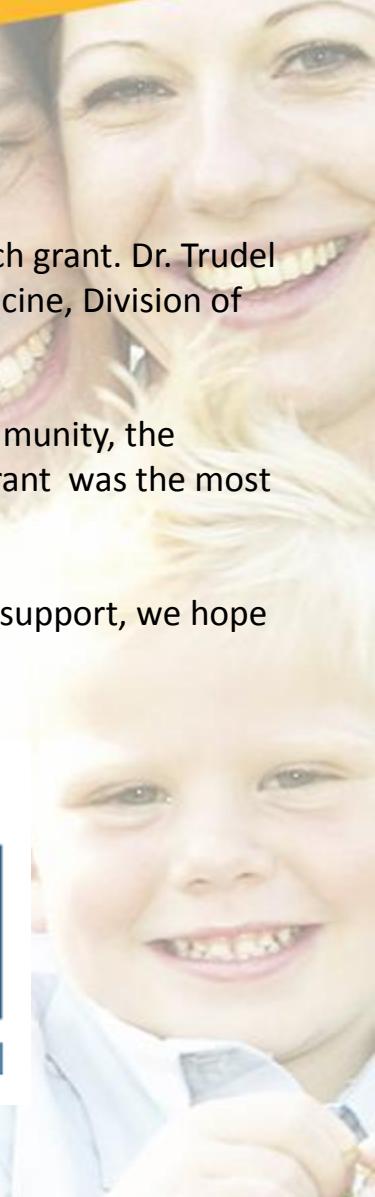
| Year | Award | Researcher | Institution | Location | Project | Amount |
|------|------------|-----------------------|---|--------------|---|---------|
| 1999 | Grant | Dr. York Pei, MD | Toronto General Hospital | Toronto, ON | Genetic modifiers for progression of ADPKD. | \$30K |
| 2000 | Grant | 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 | Signalling and modulation of polycystin-2 by Rho GTPases | \$40 |
| 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. | \$44.7K |
| 2012 | Grant | Dr. Marie Trudel, PhD | Clinical Research Institute of Montreal | Montreal, QC | In vivo analysis of ADPKD pathologies for development of therapies. | \$44.7K |

2012 Grant Recipient

In 2012, the PKDFOC was proud to support the second year of Dr. Marie Trudel's two-year research grant. Dr. Trudel is a Professor at the University of Montreal and an Associate Member of the Department of Medicine, Division of Experimental Medicine.

After an extensive review of all submitted funding proposals from the Canadian PKD medical community, the PKDFOC Board of Directors and our independent Scientific Advisory Committee felt Dr. Trudel's grant was the most sound investment and provided the best value in Canadian clinical research.

It is encouraging to see an ongoing interest in PKD research across Canada. With your continued support, we hope to further fund world-class projects in the very future.



Public Awareness

Thanks to the continued support of Rogers Communications (recipient of the 2011 Helene Kenigsberg Award of Excellence) PKDFOC staff, local PKD patients and volunteers were able to secure five on-air televised interviews as part of Rogers *daytime* programming. These segments aired across the Greater Toronto Area, York and Peel Regions of Southern Ontario, in addition to Rogers *daytime online*.

Topics discussed included:

- ▶ Living with Polycystic Kidney Disease
- ▶ National Kidney Month and World Kidney Day awareness
- ▶ The importance of organ and tissue donation
- ▶ Areas of support provided by the PKDFOC on a local and national level, and details surrounding our signature fundraising campaign - the Walk for PKD

Opportunities such as these help strengthen the PKD Community by providing an avenue to share their stories, while also helping to put a face to this common yet often unheard of disease.



2012 Helene Kenigsberg Award of Excellence

We are pleased to award the 2012 Helene Kenigsberg Award of Excellence to Continuum Productions! Over the past three years, the PKD Foundation of Canada has benefitted from incredible exposure by exhibiting at the Ideal Home and Garden Shows in Hamilton, ON. These shows, organized by Dwayne McKillop and his team at Continuum Productions, take place twice annually. They are the largest home and garden shows in Southwestern Ontario and generate over 45,000 attendees per 4-day show.

Continuum Productions has proven themselves to be a phenomenal partner in the promotion of PKD awareness and support of local PKDFOC Chapters. With the assistance of this in-kind booth space, the PKDFOC has been able to connect with a great number of PKD patients from across Southwestern Ontario and provide them with the support we offer on a local level. As such, this year's panel of judges agreed that Continuum Productions was highly deserving of the 2012 *Helene Kenigsberg Award of Excellence*.



Thanks to community-driven organizations like Continuum Productions, more and more people are learning about this disease and how they can get involved in their local PKD community. On behalf of the entire PKD Foundation of Canada, we wish to thank Dwayne McKillop and Continuum Productions for their commitment in supporting the PKDFOC's efforts to educate the masses about PKD and the support provided by our organization.

2012 Helene Kenigsberg Award of Excellence (continued)



"We were humbled and honoured to be chosen as the recipient of the 2012 Helene Kenigsberg Award of Excellence in promotion of PKD Awareness. As Southwestern Ontario's largest consumer event producers, Continuum Productions believes in giving back and supporting the communities that we live and work in.

Having access to thousands of people on a regular basis during each of our events, we were moved and motivated to support the PKDFOC and work to make the public at large more aware of this cause for those touched by PKD. We have witnessed many touching conversations at our shows and enjoyed the satisfaction of knowing our events were making a difference to many families looking for information, answers and direction.

Thank you again for bestowing this wonderful award on our company."

*Dwayne McKillop
President, Continuum Productions*

Public Awareness of Polycystic Kidney Disease

In May, Vancouver Chapter Coordinator Philip Rosario was the subject of a 4-part installment on Global BC; detailing his need for a kidney transplant and the steps leading up to finding a donor in Oak Harbor, WA Mayor, Devere Scott Dudley. Having never met before, Mayor Dudley decided to donate his kidney to Philip after hearing his wife speak at a Rotary meeting he attended in British Columbia. Through extensive testing, it was determined he was a near-perfect match!

Global BC cameras captured many touching moments between Philip and Mayor Dudley; including their first time meeting and a few post-transplant chuckles they shared with loved ones. Appreciating the significance this cross-border kidney transplant had on PKD and organ donation awareness, the Rosario-Dudley transplant story was picked up and shared by countless news agencies across North America!

A very special thank you goes out to the Rosario and Dudley families who were willing to share their personal PKD journey with an international audience!



L-R: Keesha + Philip Rosario,
Mayor Scott Dudley and his wife,
Christine

PKDFOC Local Chapters

The PKD Foundation of Canada is the only national organization solely devoted to raising funds and awareness towards finding a treatment and cure for PKD. Another important aspect of the PKDFOC is to ensure that support systems are available for those afflicted with PKD.

Volunteer Chapters serve an important role in the PKD Foundation of Canada. They are the front-line advocates responsible for creating a community of support within each region they represent. They are often the first point of contact for individuals searching for information and support regarding Polycystic Kidney Disease. Our chapters allow those affected by PKD, their friends and family to stay connected to the PKD community. We are proud to have five chapters, including: Toronto (ON), Ottawa (ON), Hamilton (ON) Vancouver (BC), Cornerbrook (NL) and an ARPKD specific online support system.

Our support group meetings, led by volunteer Chapter Coordinators, provide individuals with a place where they and their loved ones can:

- Talk to others who find themselves at similar stages of their PKD journey.
- Learn from and become inspired through fellow members' personal experiences.
- Exchange ideas and express concerns.
- Learn from guest speakers and have an opportunity to connect with top medical professionals.
- Strengthen and understand the value of their personal self-advocacy initiatives

Further access to information and peer support is provided through our national toll-free hotline (1-877-410-1741).

Local Chapter - Support Meetings

The Volunteer Chapters serve an important role in the PKD Foundation of Canada. They are the front-line advocates and often the first point of contact with new PKDFOC members. Chapters serve the specific purpose to identify and engage in active local communities.

Local chapters aim to host between four to six support group meetings per year. These are volunteer-driven educational events to help members better manage their disease by providing them with insightful information.

Topics discussed over the course of 2012 included:

- The Basics of PKD;
- Kidney Nutrition Essentials;
- What's New in PKD Research;
- Pediatric Transplantation;
- Keeping Positive with PKD
- Fertility and PKD
- Naturopathy and PKD

Meetings feature guest speakers who are leading professionals in the medical and PKD Community. Over the course of the past year they included: Renal Dieticians, organ donors transplant recipients, Chief Nephrologists and professors who are specialists in PKD-centric fields.

Chapter Updates

The PKDFOC has now been operating as a national organization for over one year. The positive feedback from both our rebranding and strengthened national presence has been overwhelming. We have been able to connect with more members of the PKD community than ever before; providing them with the support our organization offers.

We successfully launched our first west coast chapter in Vancouver, British Columbia; bringing PKD awareness and advocacy to an area previously untapped. With Philip Rosario at the helm and quarterly educational meetings already underway, residents in the lower BC area are already feeling the positive effects of having a local PKDFOC chapter!

Both our Toronto and Hamilton chapters continue to host six educational support group meetings per year, with record attendance growth throughout the year. Over this past year, each chapter secured a wonderful variety of medical professionals with an interest in PKD to speak with their members.

The Foundation also recruited new Ottawa Chapter Coordinator, Stuart Trier, who reintroduced quarterly educational support meetings; their primary means of engaging and educating local PKD patients.

Corner Brook Chapter Coordinator Nina Young continues to advocate for PKD awareness on a local level; while also acting as a support system for those residing in other areas of the east coast that do not benefit from having a local PKDFOC chapter.

New Vancouver Chapter

"Early in 2011 while in Calgary on business, I experienced some shortness of breath and gurgling in my lungs. These symptoms challenged my ability to sleep for three days, and continued when I arrived back home as well. I looked at my wife and finally said, 'It's time I go see the doctor.' Our family doctor advised I go to the emergency room immediately. Five days later while in the ICU, I was diagnosed with PKD. It was the first time my family and I had heard of this incurable disease.



My journey has lead me to meet others like myself, for which I am very thankful. Through my many appointments at both the Kidney Care Clinic and the clinics at Vancouver General Hospital, I have met transplant patients and others who are waiting for a donor while on dialysis. I have heard their stories and have shared mine. I can see the importance and comfort sharing one's journey can bring to another person.

Many miracles and angels have touched my life. My wife who is one of them, lead me to my second angel, Rotarian and hero – DeVere Scott Dudley. He is my living kidney donor. His incredible act of kindness impacted my life and that of my friends and family. Being given this gift has made me appreciative and eager to give back in any way possible.

The PKD Foundation of Canada is an amazing organization. Once we connected with the PKDFOC, I learned there was a need for a Vancouver Chapter. I saw right away that my unique story should be a part of this. I am proud to be participating in the role of Vancouver Chapter Coordinator. Being a Chapter Coordinator has allowed me to make a difference and continue to bring others like me together. Raising awareness about this disease is important to me, as is helping others cope with it. I look forward to bringing together more PKD patients and sharing our stories in a journey to discover treatments and a cure for polycystic kidney disease."

New Ingleside Walk Coordinator

"While attending the 2011 Walk for PKD in Vankleek Hill, I was approached by Walk Coordinator, Cheri Barton who asked if I would be willing to take on the Walk for PKD the following year to give her a much needed break. I was not sure if I could take it on in the Kingston area, but my sister thought it would be great to host the event in Ingleside; her current hometown.

We were blessed with a great committee and a supportive community , and had a very successful Walk for PKD. We held two bake sales that same year at the Long Sault Farmer's Market, a fundraiser through 'Pampered Chef' and a silent auction on Walk Day. All of these events, along with the support of registered Walkers, helped us to raise over \$25,000 to help find a cure for PKD! Cheri raised over \$12,000 independently; thanks to many wonderful friends, family in Vankleek Hill. We were also able to get a few corporate sponsorships as well and will always be grateful for their generosity!

I have a new appreciation for Cheri and all Chapter & Walk Coordinators, who year after year take on this task and do it with such grace."

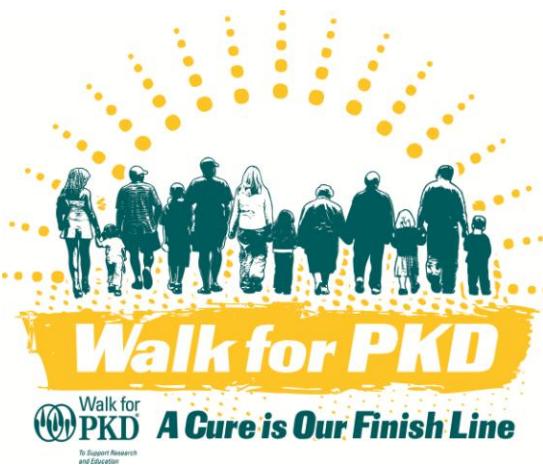
- Phyllis Hume, Ingleside Walk for PKD Co-Coordinator



Fundraising

The 2012 Walk for PKD, our signature fundraising event, was once again a record-setting campaign for the PKD Foundation of Canada in both funds raised and participants on-site! Each specific walk saw an impressive increase in funds raised from the previous year. The Guelph Walk for PKD, in only it's second year, raised 61% more than in 2011; and the Ottawa Region (Ingleside) and Toronto Walk for PKD events increased their fundraising efforts by 57% and 19% respectively. Through the tireless efforts of our participants and their generous donors, over \$95,000 was raised; an impressive 32% increase from 2011.

In addition to the Guelph, Ottawa Region and Toronto Walk for PKD events, each volunteer Walk Coordinator hosted a number of pre-Walk fundraisers to help increase visibility of PKD; while also kick-starting their fundraising efforts. These initiatives included countless bake and craft sales; a *Pampered Chef* event; a Walk for PKD launch party; two silent auctions, a number of 50/50 raffles and an *NHL Winter Classic* raffle. It is no surprise that through the hard work put forth by all involved in these fundraisers that we were able to see the growth we did in our national campaign.



Fundraising (continued)

The PKD Foundation of Canada was privileged to have the support of many great corporate sponsors this year. Corporate sponsors support us and strengthen our efforts to raise awareness of ultimately finding a cure for PKD. We could not successfully put on these events and direct your hard earned contributions where the donor intends for them to go – towards a cure – without their support.

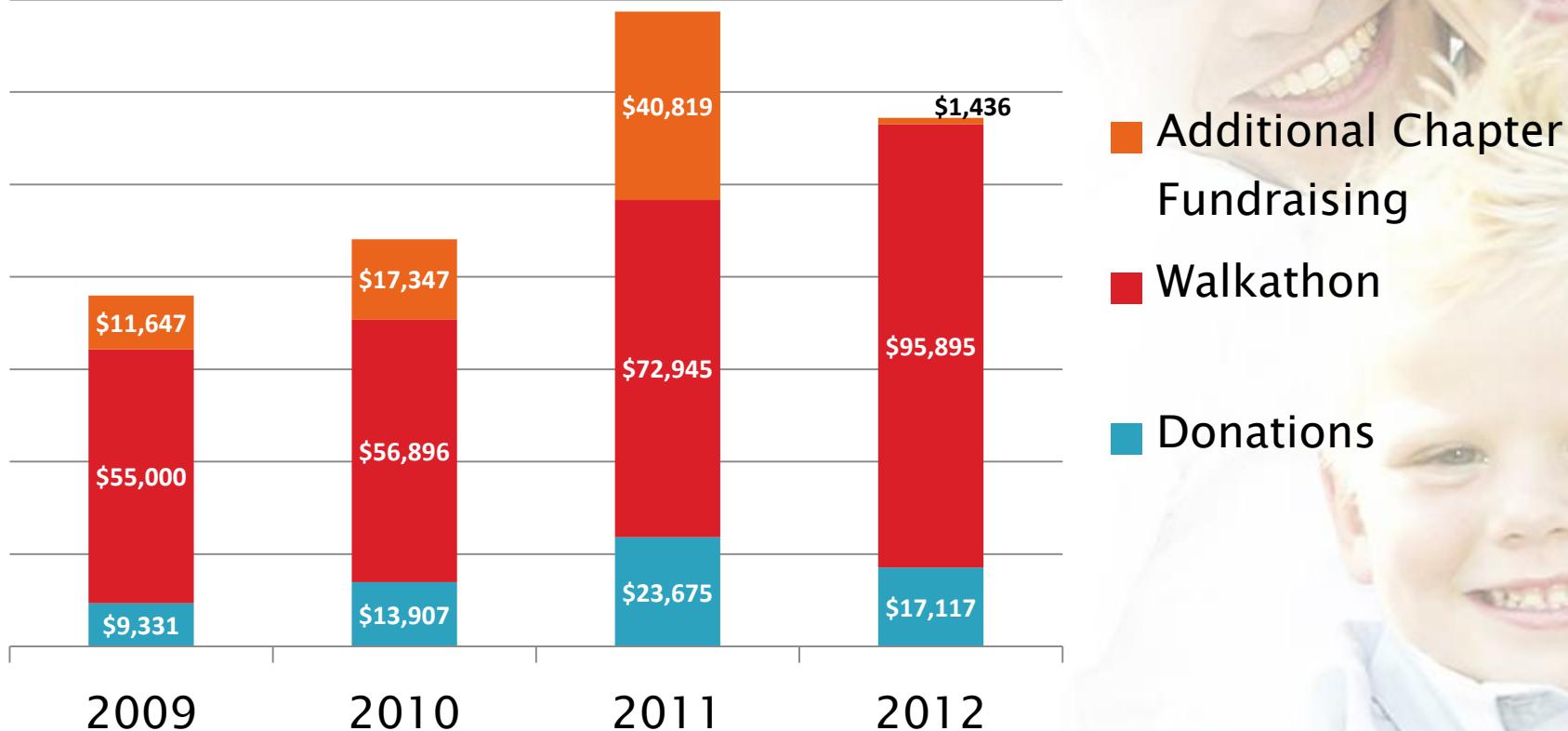
In 2012, Mohawk Foods became our second **Gold Level Corporate Sponsor** to date; donating \$3,000 to the Walk for PKD campaign, as well as providing in-kind baked goods for the participants to enjoy!

A big thank you to Mohawk Foods for aligning themselves with the PKDFOC and helping to make an incredibly positive impact in the local PKD Community!



Mohawk Foods

2012 Comparative Contributions



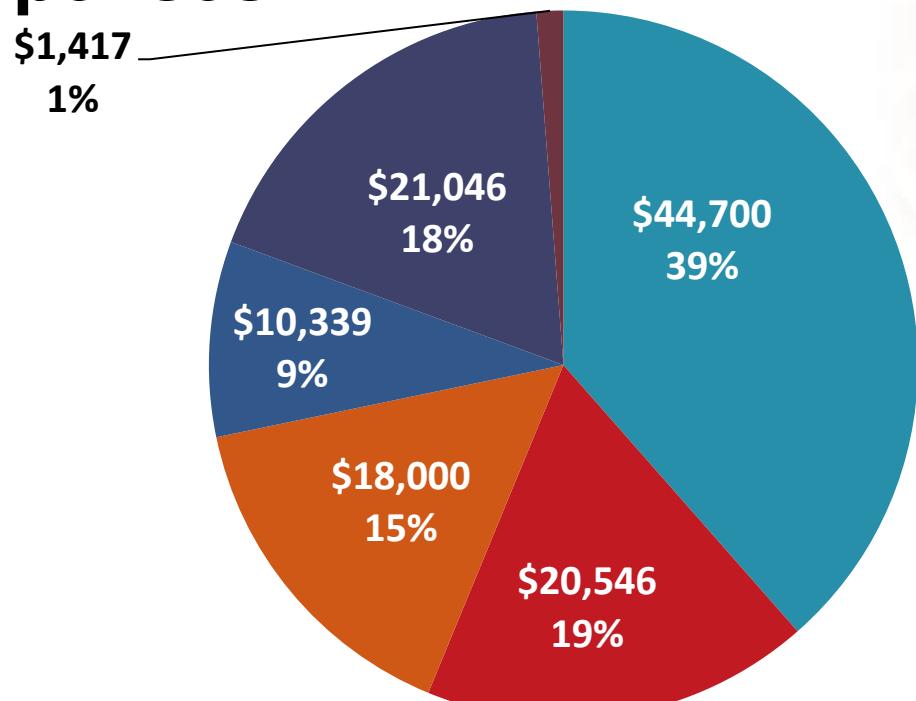
- Additional Chapter Fundraising
- Walkathon
- Donations



* 2009 and 2010 fundraising values include Ottawa Chapter fundraising events which did not take place over 2011 and 2012.

* 2011 fundraising values include the one-time Richmond Hill Mayoral Golf Tournament revenues which were \$40,000.

2012 Expenses



■ PKD Research Grants

■ Member Services and Education (support meetings, webinars, PKD phone line, newsletters, PKD brochures: development and distribution)

■ Fundraising (costs associated with fundraising events)

■ Chapter Management (establishing / training / ongoing support)

■ Foundation Growth / Development (website development, conference attendance, public awareness initiatives)

■ Legal and Insurance

A total of \$49,308.72 (staff salary) has been allocated into areas where the E.D's time and attention has been focused.

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A Heartfelt Thank You to Our Donors & Volunteers!

2012 was another amazing year for the PKD Foundation of Canada as we continued to see substantial growth from both a Chapter and a Foundation standpoint. This allowed our volunteer-driven organization to provide more support than ever before to PKD patients and their loved ones across Canada.

Our triumphs could not be achieved without the dedication of our generous donors, and the tireless efforts put forth by our local Chapter & Walk Coordinators and volunteers.

It is because of your vital support that we are able to further advance research into discovering a treatment for polycystic kidney disease. From everyone here at the PKD Foundation of Canada: a million thanks to you for joining us in the fight to END PKD!



(Above) The 2012 Ingleside Walk for PKD