

The PKD Research Society of Canada Annual Report 2010



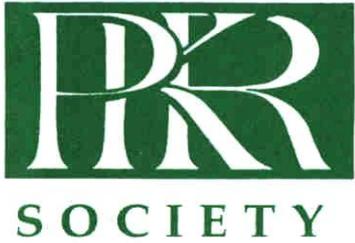
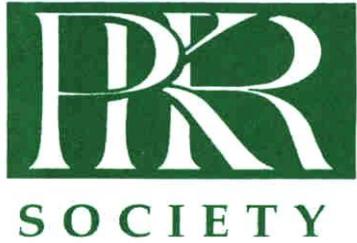


Table of Contents

	Page
➤ Message from the Chairman	3
➤ Message from the Executive Director	4
➤ The Organization	5
➤ The Board of Directors and Staff	6
➤ Rebranding the PKDROC	7
➤ 2010 Grant Recipient	8
➤ Grant History	9
➤ Support Meetings and Member Education.....	10
➤ Public Awareness	14
➤ Chapter Management	18
➤ Fundraising	19
➤ Finances	20



Message from the Chairman of the Board

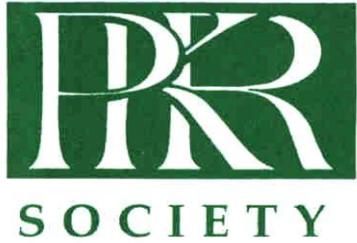


In 2010 the Polycystic Kidney Disease Research Society of Canada (PKDRSOC) has made great strides in making our organization a much stronger, more accessible and responsive charitable foundation:

- We have continued to offer even more PKD specific webinars and with the continued support of live speakers from the PKD medical community, our bi-monthly support group meetings have been well attended and become even more informative.
- The monthly e-Newsletter our Executive Director publishes has been well received by our members and continues to be very informative.
- We have had a great deal of media exposure on PKD over the past year, (television interviews, paper and online newspaper articles, radio interviews and special event spotlights).

All of these accomplishments have been achieved through the hard work and dedication of our Executive Director Jeff Robertson and a core group of volunteers. The Board of Directors of the PKD Research Society of Canada thanks you all and looks forward to working with you in 2011.

Best Regards,
Doug Robertson
Chairman of the Board of Directors, PKD Research Society of Canada



Message from the Executive Director



2010 proved to be the best year yet for the Polycystic Kidney Research Society of Canada. With the creativity and dedication of our volunteer base, we saw significant advancements in both Polycystic Kidney Disease awareness and fundraising initiatives from across the country; making 2010 our greatest fundraising year to date!

In a continued effort to best serve those afflicted with PKD in Canada, we've rebranded what was once a provincially driven organization (the PKD Research Society of Canada) as a national charity, the PKD Foundation of Canada (PKDFOC). This new branding measure, including the incorporation and registration as a national charity, allows us to raise both funds and awareness through new local support group initiatives on a national level.

I am proud to say that the PKDFOC now has not only a Facebook Fan Page and Twitter account, but also a comprehensive Canadian website (www.endpkd.ca). This is a significant step forward in connecting us to you, and you with the information you need on PKD and your local Chapter! Going forward, we hope to leverage these tools to expand our community and service your needs better.

This year's \$25,000 award to Dr. York Pei is the first step to enhancing the research and educational capacity of the PKD specific clinic at Toronto General Hospital. We are so excited to be able to contribute to the world class research that this clinic produces!

I have the utmost faith that 2011 will bring even greater achievements and I look forward to continuing my work with the amazing individuals from the PKD Community in a collective effort to END PKD!

Warm Regards,
Jeff Robertson
Executive Director, PKD Research Society of Canada



The Organization

Polycystic Kidney Disease Research Society of Canada (PKDRSOC)

3 – 1750 The Queensway, Suite 158

Etobicoke, Ontario M9C 5H5

Tel: 416.410.1740

Toll Free: 1.877.410.1741

Email address: endpkd@endpkd.ca

Mission Statement

The mission of the PKD Research Society 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

Our vision is that **no one suffers the full effects of PKD.**

Governance

The PKD Research Society of Canada is a registered Canadian Charitable Organization (BN: 870176831RR0001)

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



The Board of Directors and Staff

Board Members in brief:

Chairman

Doug Robertson is a senior manager in the consumer packaged goods industry and has served as a Board Member of PKDRSOC since its inception in 1994.

Secretary

Odette Bulaong is a Licensed Naturopathic Doctor and has been a member of the PKDRSOC for several years and a member of the Board of Directors since 2009.

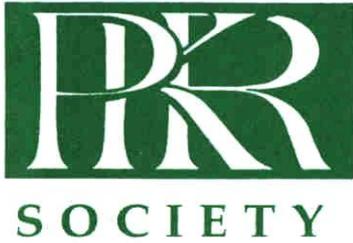
Treasurer

Eva Higgison has over 8 years experience as a Bookkeeper and is working full time while finishing her Accounting Degree. Eva joined our Board in 2009.

Staff:

Executive Director

Jeff has been the Executive Director of the PKDRSOC since July 2008. He is the sole paid staff member and takes on many of the day to day managing and coordinating responsibilities of the charity. Jeff is also the front line contact for the PKDRSOC and is responsible for the creation and implementation of many of our long-term strategic initiatives.



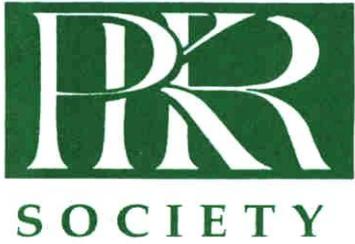
Rebranding the Polycystic Kidney Research Society of Canada



The Polycystic Kidney Research Society of Canada is proud to announce that we have officially incorporated as the Polycystic Kidney Foundation of Canada! In early 2011, after we receive national charitable status we will begin operating under our new name.



In 1993, when the PKRSOC was formed it received charitable status in Ontario. With recent expansion and our goals of providing services across Canada, it became necessary to be registered as a nationwide charity. The name change aligns us with our larger American cousins, building name recognition and reducing branding costs by allowing us to share some of their educational material. **Rest assured we continue to be are our own, separate and independent charity which is here to service the needs of Canadians!**



2010 Grant Recipient

The PKDRSOC was proud to award a \$25,000 infrastructure grant to Dr. York Pei. Dr. Pei is a Professor of Medicine at the University of Toronto and a Staff Nephrologist and Senior Scientist at the Toronto General Hospital. This grant will enhance the PKD research and educational capacity of his clinic at the Toronto General Hospital which sees approximately 400 PKD patients annually.



From L-R: Treasurer, Eva Higgison; Chairman, Doug Robertson; Dr. York Pei; Executive Director, Jeff Robertson

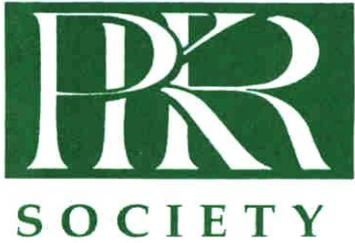


PKD Research Society of Canada Grant History (1999-2010)

The PKDRSOC works with the PKD Foundation's Scientific Advisory Committee (made up of top PKD medical experts from around the world) to ensure the highest calibre of Canadian research is funded!

Project Year	Award	Researcher	Institution	Location	Project	Named Donor	Amount
1999	Grant	Dr. York Pei, MD	Toronto General Hospital	Toronto, ON	Genetic modifiers for progression of ADPKD	PKD Research Society of Canada (PKDRSOC)	\$30,000
2000	Grant	Dr. Marie Trudel, PhD	Clinical Research Institute of Montreal	Montreal, PQ	Molecular genetics of PKD1 Gene: analysis of the extracellular domain	PKDRSOC (\$40,000) & PKD Foundation - USA (PKDF-USA) (\$10,000)	\$50,000
2003	Grant	Dr. Zhen Chen, PHD	University of Alberta	Edmonton, AB	Structure-function and regulation of polycystins and fibrocystins	PKDRSOC	\$32,000
2007	Fellow-ship 2nd yr	Dr. Qiang Li, PhD	University of Alberta	Edmonton, AB	Signalling and modulation of polycystin-2 by Rho GTPases	PKDRSOC (\$40,000) and PKDF-USA (\$10,000)	\$50,000
2010	Grant	Dr. York Pei, MD	Toronto General Hospital	Toronto, ON	Patient registry database to enhance PKD research capacity	PKDRSOC	\$25,000

The PKDRSOC was thrilled to award a grant in 2010! We still have considerable money set aside for PKD initiatives and are considering proposals of all sizes for 2011. We hope to continue to fund worthy projects and to see more Canadian grant applicants in the future.



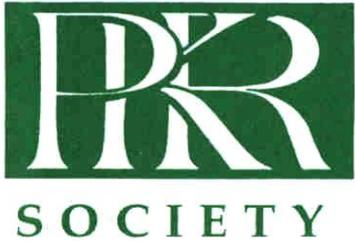
Support Meetings

The PKD Research Society 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 PKDRSOC is to ensure that support systems are available to those afflicted with PKD.

Our chapters and support groups allow those affected by PKD, their friends and family to stay connected to the PKD Community. Access to a variety of information and peer support is also provided through our national toll-free hotline (1-877-410-1741). We are proud to have four chapters including: Toronto (ON), Ottawa (ON), Vankleek Hill (ON) and Cornerbrook (NL).

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.



Member Education

In 2010, we continued to offer high calibre guest speakers for those able to attend our area support groups and, for those too far away, interactive webinars led by prominent medical professionals. Our existing local support group and educational meetings continue to generate a positive response and, due to demand, our Toronto Chapter has doubled its meeting frequency.

Our 2010 Webinars were presented by:

- Howard Winokuer, MD (Head of The Winokuer Center in Charlotte, NC and Co-founder of the not for profit TO LIFE) who spoke on understanding loss and managing grief.
- Marie Hogan, MD, PhD (Assistant Professor of Medicine at the Mayo Clinic in Rochester, MN) who spoke on Polycystic Liver Disease and its links to PKD.
- York Pei, FRCPC, MD (Staff Nephrologist and Senior Scientist at Toronto Western Hospital in Toronto, ON) who spoke on ADPKD related complications.
- Theodore Steinman, MD, MA (Beth Israel Deaconess Medical Center) who spoke on the causes of pain and PKD.
- Harvey Mysel (President and Founder of The Living Kidney Donors Network) who spoke on the importance of living kidney donors and the critical need for living organ donation.
- Ben Cowly, MD (University of Oklahoma Health Sciences Center in Oklahoma City, OK) who spoke on the fundamentals of dialysis.



Member Education (continued)

Our 2010 Guest Speaker's included:

- Dr. David Chitayat, MD (Professor at University of Toronto and geneticist at Mount Sinai and Sick Kids Hospital) who spoke on the genetics of PKD.
- Dr. York Pei, FRCPC, MD, MSc (Senior Scientist in the Division of Genomic Medicine at Toronto General Hospital) who provided us with an update on current and upcoming clinical trials of ADPKD drug treatments.

Additionally, topics were covered at other meetings including understanding dialysis, Polycystic Liver Disease, the PKD Foundation UAS's National Convention summary and chapter open forums.

The PKDRSOC is tremendously thankful to all of our great speakers and the PKD Foundation (USA) for producing the webinars. We are excited to continue providing the Canadian PKD Community with a great roster of educational speakers!



Member Education (continued)

The PKDRSOC continues to distribute the educational brochures we developed in 2009. We are glad to have these educational materials which have shown to be particularly helpful to those who are newly diagnosed!



'PKD: What Every Family Needs to Know' and *'Your Guide to Living with PKD'* are both branded with the PKD Foundation of Canada contact information recognizing the upcoming 2011 organizational changes!



Public Awareness

PKD in the media

It's our mission to get the word out on PKD and the PKDRSOC to those who can use our services, and in an effort to increase awareness of Polycystic Kidney Disease in Canada.

PKD Research Society of Canada had members appear on Rogers Daytime, Rogers TV's most popular LIVE lifestyle magazine program, nine times in 2010! This is up from the three spots we were privileged to receive in 2009. Each 15 minute segment aired three times daily and helped us enhance PKD awareness throughout the Greater Toronto Area and promote fundraisers, educational seminars and support meetings.

In March 2010 our Executive Director Jeff Robertson was featured in the Good News Toronto newspaper and their online website for his efforts within the PKDRSOC (issue 2, volume 3). This article was exciting progress for us as it showcased the positive impact our Foundation has had on the local community and reached a younger demographic than our other efforts.

This year's media coverage resulted in increased awareness and new members which make our organization even stronger!



Public Awareness (continued)

On September 25th 2010 Toronto Chapter Co-ordinator Joseph Brant was featured in a PKD related article in the Saturday edition of The Toronto Sun. Joseph discussed his feelings about being a new parent and in turn did a great job increasing public awareness of PKD and the Toronto Walk!

Dad walks for hope – and Juliette’s health

JENNY YUEN
Toronto Sun

Joseph Brant prepared for the worst while he awaited the birth of Juliette, his first daughter.

He was diagnosed with polycystic kidney disease (PKD) when he was 16 — the same year his father died of the disease — and he was afraid the hereditary illness would be passed onto his firstborn.

“The immediate fears were Down syndrome and all these other birth defects when you’re pregnant — even though that’s not what we were talking about, emotionally, some of that stuff bubbles up,” said the 33-year-old Brant, who is a co-ordinator for the Toronto chapter of

the Polycystic Kidney Disease Foundation of Canada.

“She was born in March 30 of this year and weighed 9½ pounds. She came out crying, happy and seemingly healthy.”

But after an ultrasound test, it was confirmed Juliette had the PKD1 gene.

Brant is walking for Juliette and future generations on Sunday. He will join hundreds of others at the 9th annual Toronto Walk for PKD to spread awareness of the disease.

“We were prepared for it, so it wasn’t a big shock,” Brant said. “We’re familiar with

the disease and even though it doesn’t have a cure, we’re staying positive. We just need to continue to see the nephrology people at Sick Kids and doing what we can do help her.”

“We’re familiar with the disease and even though it doesn’t have a cure, we’re staying positive”

Joseph Brant

around the world.

There are two types of PKD: Autosomal dominant PKD is the most common inherited form. Symptoms usually develop between the ages of

30 and 40, but they can begin earlier, even in childhood. Roughly 90% of all PKD cases are that strain.

The second is autosomal recessive PKD and is a more rare inherited form. Symptoms begin in the earliest months of life, even in the womb. Anyone who thinks they might have kidney problems should regularly meet with a nephrologist, the foundation said.

There are over 50 walks worldwide going on September through to November. Organizers of Toronto’s walk at Centennial Park hope to raise \$45,000.

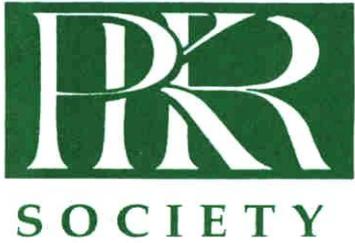
For more information about the walk, call 1-877-410-1741 or go to www.endpkd.ca.

jennyuen@sunmedia.ca



MICHAEL PEARNE/TORONTO SUN

Joseph Brant, who suffers from polycystic kidney disease, holds his five-month-old daughter Juliette, who also has PKD.

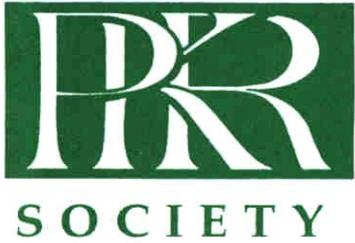


Public Awareness (continued)

In 2010 the PKD Research Society of Canada was excited to award the first ever *Helene Kenigsberg Award for Excellence in Public Awareness of Polycystic Kidney Disease* to the book “**My Favorite American**”. “My Favorite American” details the personal story and challenges of Valen Cover’s journey with PKD. Author and Richmond Hill native Dennis McCloskey attended a Toronto Chapter meeting to accept a plaque commemorating the award.



From L-R: Toronto Chapter Coordinator, Joseph Brant; author Dennis McCloskey; Executive Director, Jeff Robertson



Public Awareness (continued)

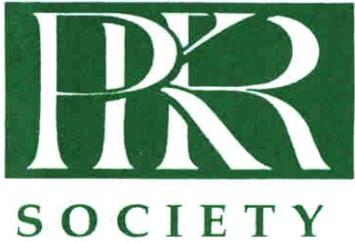
During March's National Kidney Month in 2010, a team of 4 volunteers represented the PKD Research Society of Canada at an informational booth at the **Ideal Home & Garden Shows** in Hamilton and Ottawa, Ontario. Over 100,000 people attended these home shows and we were able to connect with many families afflicted by PKD who were previously unaware of our organization and the support we provide!

Our booth space was generously donated by RE/MAX Realty. We thank RE/MAX Realty and Continuum Productions for their generosity and continued support and we look forward to attending the 2011 shows!



March 3-6, 2011



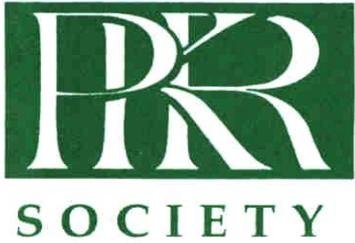


Chapter Management

We are proud to announce that we have officially incorporated nationally! This national incorporation is the first step in starting volunteer driven chapters across the country. Our Toronto Chapter has doubled the frequency of its support group meetings and our annual attendance. Due to changes in the Ottawa volunteer base we were unable to expand this year. Fortunately, with our Executive Director acting as interim Coordinator we were able to keep our Ottawa Chapter open and active! We hope to find a replacement volunteer coordinator soon and continue expanding through developing chapters nationwide! We are proud to still have four active volunteer based chapters and we look forward to continuing to assist these groups in their efforts to raise awareness and provide support to those with PKD!



2010 Vankleek Hill Walk for PKD

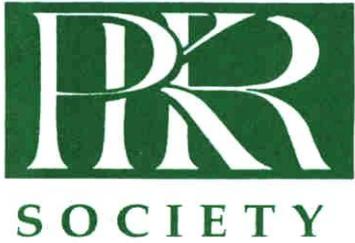


Fundraising

In 2010 we continued to grow our core fundraising events and our volunteers took the initiative to introduce a number of new and innovative events . The PKDRSOC appreciates our donor and volunteer commitment and once again their enthusiasm was seen in the events they were involved in! In the past year, our members have:

- Supported 7 fundraising events (Ultrasound Dance Party, Avon holiday ornament campaigns etc.).
- Raised \$57,000 through our signature fundraising campaign The Walk for PKD, in Toronto and Vankleek Hill (Ottawa region).
- The Toronto walk had 23 registered teams (many showing up in costumes !) and the two events had over 350 participants. We are once again extraordinarily thankful for the support from local volunteers and corporate sponsors!
- The Ottawa Chapter ran a successful Cease + Decyst Fundraiser raising \$14,500, a 70% increase from 2009. This event had live entertainment, dinner, auctions and 50/50 tickets!

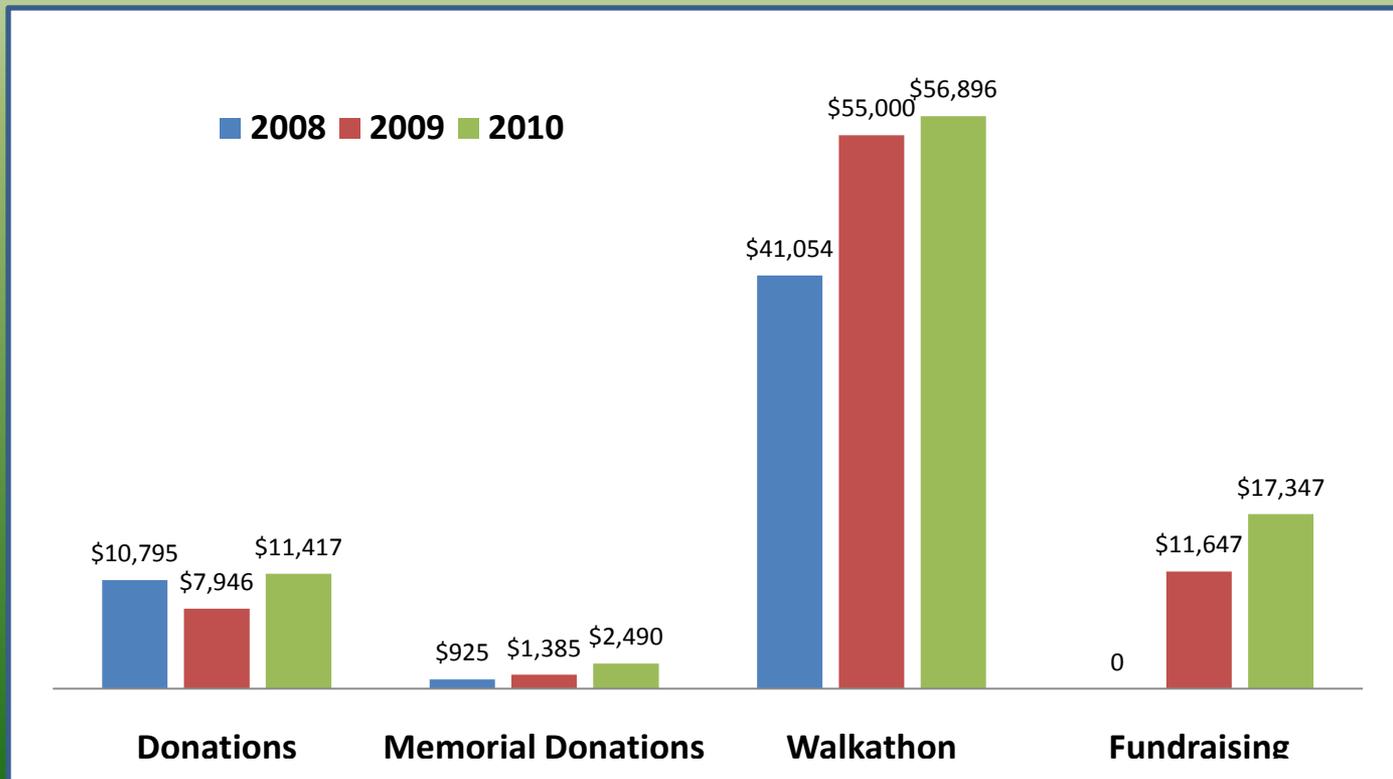
This continued support will assist us in meeting the needs of Canadians who are impacted by PKD while allowing us to continue strengthening our national presence and bring awareness to PKD.

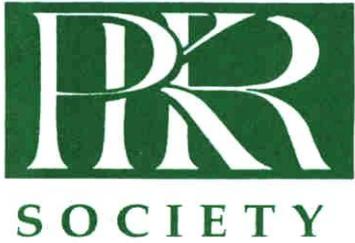


Finances

We value the investment our donors make to the PKD Research Society of Canada. We are thrilled to see substantial growth in your contributions and we look forward to providing support to our community and contributing to valuable research.

Comparative Contributions

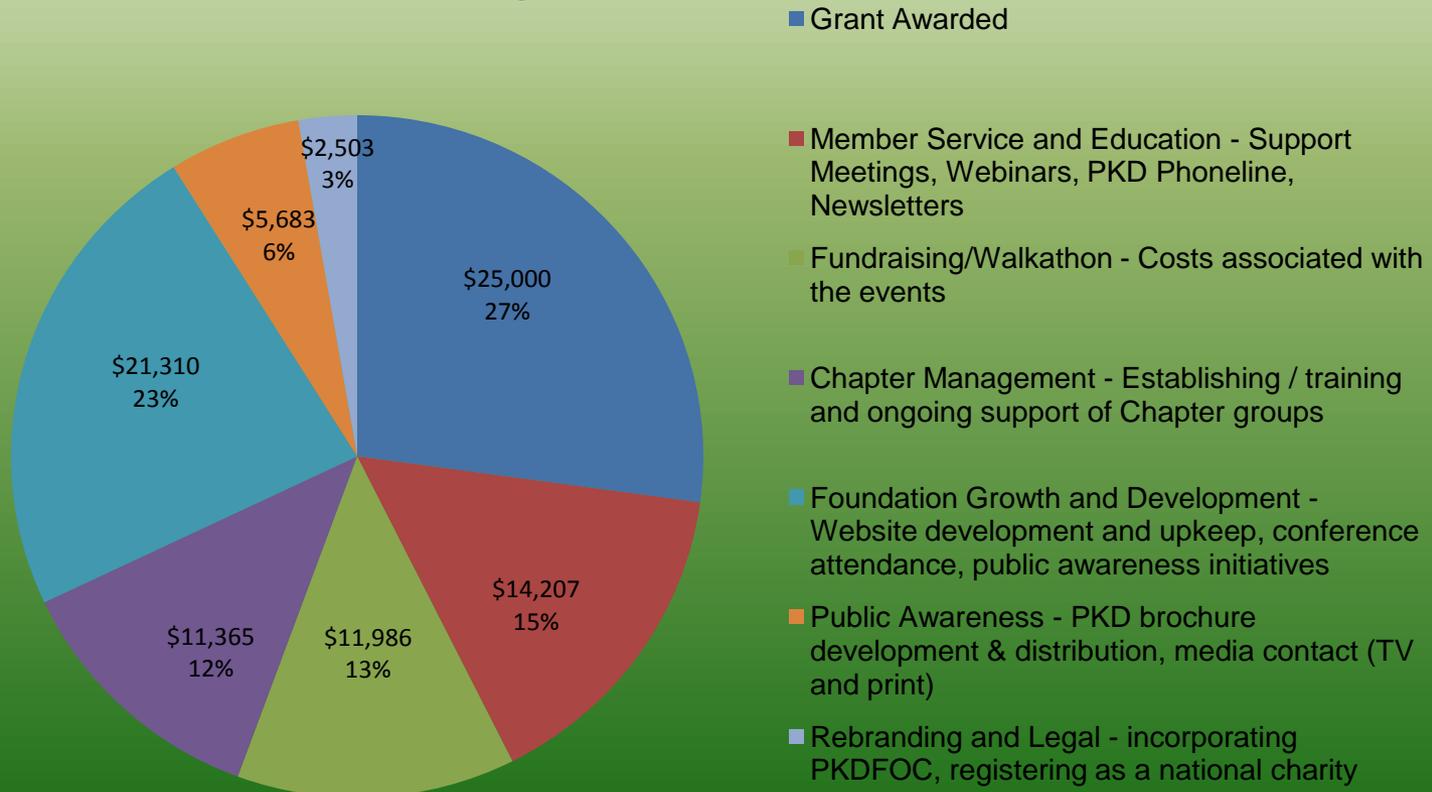


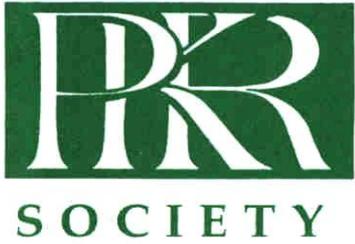


Finances (continued)

We ensure that the funds we receive directly benefit our frontline programs, services and research initiatives. We target our funds towards helping Canadians living with Polycystic Kidney Disease. *A total of \$44,275 (staff salary) has been allocated into areas where ED time & attention has been focused.*

How funds were allocated / 2010 Expenses





A Heartfelt Thank You

2010 brought many great successes to the PKD Research Society of Canada. As always, the Board of Directors wishes to thank our generous donors, tireless volunteers and our Executive Director. Without your support and effort we wouldn't be able to offer the services, support, and grants that help, and give hope to, those afflicted with PKD.

