The PKD Foundation of Canada
2013 Annual Report
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From the Board of Directors

On behalf of the Board of Directors, the researchers and the patients and their families, I’d like to thank you very much for your financial support, the time spent at various PKD Foundation of Canada events, and the time you have spent supporting patients through disease management, lifestyle support and educational activities.

Last year our Chairman outlined the following objectives for the Foundation:
• Increase our contributions to primary research and one day find a cure for PKD
• Expand our support and outreach to those afflicted with PKD and their families and support circles
• Ensure more Canadians know what PKD is and how we can all help people who suffer from it

In the short time that I have served on this Board, I am constantly amazed at the level and the intensity of the dedication and effort of everyone involved in the polycystic kidney disease community.

The researchers that we have supported have been awarded almost $300,000 in research and fellowship funding since the Foundation has been established. For a relatively new Foundation serving a growing number of patients in Canada, the contribution to the body of research work fighting this disease state in Canada is outstanding.

Additionally, the support from people who come out for our Walk for PKD campaign and other fundraising events has been truly incredible. We will get to the end point of our process sooner if this support continues to grow on the track it has over the past few years. Thank you again for being part of this noble process.

Christopher Neuman B.Sc., B.Comm., MBA
PKD Foundation of Canada Board Director
From the Executive Director

Since taking on the role of Executive Director in 2008, we as a Foundation have worked diligently to increase the level of support and educational information provided to the PKD community, funding of critical Canadian research and the promotion of PKD advocacy on a local and national level. In five years, we have:

- Developed a comprehensive membership of engaged PKD patients and their loved ones
- Increased our revenue by 151%
- Reduced our operating expenses by 25%
- Funded approximately $150,000 to Canadian researchers and fellows specializing in the field of PKD; 51% of our total grants awarded since 1999.

With the development of potential treatments of PKD closer than they have ever been before, it is imperative we continue to work together to make the greatest impact possible in the PKD community. Our collective efforts to end PKD play an important role in advancing PKD research here in Canada and improving the lives of those afflicted by PKD.

I thank you for your continued support and look forward to what is in store for 2014.

Working for a cure,

Jeffrey D. Robertson
Executive Director, PKD Foundation of Canada
The Organization

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Email address: endpkd@endpkd.ca

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 seven members including a Chairperson, a Secretary and a Treasurer and four 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 has been a member of the Board of Directors since 2010. Michael currently works as a Management Consultant at a global firm focused on pharmaceutical and healthcare clients. He holds an MBA from the Richard Ivey School of Business, an MSc from the University of Western Ontario and a BSc from York University.

Secretary
Doug Robertson is a senior manager in the consumer packaged goods industry, and has served as a board member of the PKD Foundation of Canada 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.

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. Prior to joining the Board of Directors in 2012, he was the volunteer Toronto Chapter Coordinator from 2009 to 2013.

**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.

**Director**
Antonella Rizza joined the Board of Directors in January 2013. Her personal connection to PKD was first identified when her father was diagnosed with a rare mosaic form of PKD (PKD in only one kidney). Antonella is a partner in the KPMG LLP Toronto offices. She has specialized in areas of financial statement auditing, US GAAP, Private Business GAAP, International Financial Reporting Standards (IFRS) and Securities Offerings. She has experience working with public, private and not-for-profit organizations.
Board of Directors and Staff

**Director**
Christopher Neuman has over 30 years of progressive experience in the Canadian pharmaceutical, medical device, and biotech, most recently in senior executive leadership roles (12 years P&L responsibility). Amongst his many accomplishments, Chris has written clinical research protocols, led FDA submissions, launched numerous Branded and Generic products, led numerous BD activities acquiring and disposing of products and businesses, set up several national sales forces, led marketing efforts in the American and off shore markets.

**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 five years. Jeff 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.
## PKDFOC Grant History

<table>
<thead>
<tr>
<th>Year</th>
<th>Award</th>
<th>Researcher</th>
<th>Institution</th>
<th>Location</th>
<th>Project</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>Grant</td>
<td>Dr. York Pei, MD</td>
<td>Toronto General Hospital</td>
<td>Toronto, ON</td>
<td>Genetic modifiers for progression of ADPKD.</td>
<td>$30K</td>
</tr>
<tr>
<td>2000</td>
<td>Grant</td>
<td>Dr. Marie Trudel, PhD</td>
<td>Clinical Research Institute of Montreal</td>
<td>Montreal, QC</td>
<td>Molecular genetics of PKD1 gene.</td>
<td>$40K</td>
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<tr>
<td>2003</td>
<td>Grant</td>
<td>Dr. Zhen Chen, PhD</td>
<td>University of Alberta</td>
<td>Edmonton, AB</td>
<td>Structure, function and regulation of polycystins and fibrocystins.</td>
<td>$32K</td>
</tr>
<tr>
<td>2007</td>
<td>Fellowship</td>
<td>Dr. Qiang Li, PhD</td>
<td>University of Alberta</td>
<td>Edmonton, AB</td>
<td>Signalling and modulation of polycystin-2 by Rho GTPases</td>
<td>$40</td>
</tr>
<tr>
<td>2010</td>
<td>Grant</td>
<td>Dr. York Pei, MD</td>
<td>Toronto General Hospital</td>
<td>Toronto, ON</td>
<td>Patient registry database to enhance PKD research capacity.</td>
<td>$25K</td>
</tr>
<tr>
<td>2011</td>
<td>Grant</td>
<td>Dr. Marie Trudel, PhD</td>
<td>Clinical Research Institute of Montreal</td>
<td>Montreal, QC</td>
<td>In vivo analysis of ADPKD pathologies for development of therapies.</td>
<td>$44.7K</td>
</tr>
<tr>
<td>2012</td>
<td>Grant</td>
<td>Dr. Marie Trudel, PhD</td>
<td>Clinical Research Institute of Montreal</td>
<td>Montreal, QC</td>
<td>In vivo analysis of ADPKD pathologies for development of therapies.</td>
<td>$44.7K</td>
</tr>
<tr>
<td>2013</td>
<td>Fellowship</td>
<td>Dr. Moumita Barua</td>
<td>Toronto General Hospital</td>
<td>Toronto, ON</td>
<td>One-Year Hereditary Kidney Disease Fellowship</td>
<td>$35K</td>
</tr>
</tbody>
</table>
In 2013, the PKD Foundation of Canada awarded the University Health Network and Toronto General Hospital’s Hereditary Kidney Disease Clinic with a one-year translational research fellowship for Dr. Moumita Barua. This award was joint-funded by the PKD Foundation of Canada and the Tuberous Sclerosis Canada, with both organizations contributed $35,000 towards this grant.

Dr. Barua completed her training in internal medicine and nephrology from the University of Toronto in 2009. Her research focuses on the use of genome-wide linkage and exome sequencing for discovery of novel genes for familial focal segmental glomerulosclerosis (FSGS). Dr. Barua is interested to expand her clinical expertise in Hereditary Kidney Disease (HKD) with the goal of applying her research methodologies more broadly to hereditary kidney diseases beyond that of familial FSGS.

University Health Network is the largest healthcare institution in Canada and comprises of four University of Toronto affiliated hospitals, Toronto General Hospital, Toronto Western Hospital, Princess Margaret Hospital and Toronto Rehab. Within this framework, Toronto General Hospital houses the first specialty clinic in Canada dedicated to the care of patients with HKD. This clinic is currently following more than 200 ADPKD patients and their families, many of whom have participated in one or more of their research studies. This clinic is designed to couple clinical care with research so that new knowledge for the benefits of their patients can be generated.
Public Awareness of PKD

With the support of the local print and television, PKD Foundation of Canada staff, volunteers and local PKD patients were able to receive a great deal of exposure over the course of 2013. Topics covered included:

- Families searching for living kidney donors
- National Kidney Month and World Kidney Day
- Educational meetings and community events
- The Walk for PKD campaign

Coverage like this provides the PKD community with a platform to share their stories while helping to put a face to this common, yet often unheard of disease.
Public Awareness of PKD (continued)

The PKD Foundation of Canada Toronto and Hamilton Chapters benefitted from in-kind exhibition space at three high-profile Southwestern Ontario home & garden shows in 2013. Because of this invaluable visibility, the PKD Foundation of Canada was able to connect with a great number of PKD patients and introduce them to the support and services we provide. In turn, these individuals became engaged members of our local chapters to help spread the word about PKD and the Foundation.

In addition to the booth exposure this year, we were selected as the Charity of Choice for Continuum Production’s Hamilton Fall Home Show to receive all proceeds from the live and silent auction held at the show.
Public Awareness of PKD (continued)

The PKD Foundation of Canada partnered with the Trillium Gift of Life Network in Ontario this year in support of their *Gift of 8 Workplace Initiative*. Knowing that roughly 60% of those with the dominant form of PKD will rely on either dialysis or transplantation, this campaign was a great opportunity to strengthen our vision of improving the quality of life for those living with PKD.

The Gift of 8 campaign is a turnkey program developed to engage constituents in this vital cause and increase the numbers of registered organ and tissue donors in Ontario. During National Kidney Month in March, 236 individuals registered their consent to donate on the PKD Foundation of Canada’s Gift of 8 webpage.
The Helene Kenigsberg Award of Excellence in Public Awareness of PKD is the only award of its kind; honoring individuals who have made an outstanding contribution in creating public awareness of polycystic kidney disease. This award was designed to provide recognition to Canadians who deeply align themselves with the mission of the PKD Foundation of Canada.

We are pleased to award the 2013 Helene Kenigsberg Award to Vancouver Chapter Coordinator, Philip Rosario. Philip received a life-saving kidney transplant from Oak Harbor, WA Mayor, Scott Dudley. In addition to Philip securing a variety of print publications to cover this border-crossing gift of life, Global TV in British Columbia did a wonderful job showcasing Philip and Scott’s journey from start to finish.

On behalf of the entire PKD Foundation of Canada, we wish to thank Philip Rosario for his commitment in supporting our mission to educate the masses about PKD and the avenues of support provided by our organization and local Chapters.
Many miracles and angels have touched my life. My wife who is one of them, led me to my second angel, Rotarian and hero, DeVere Scott Dudley - my living kidney donor. His incredible act of kindness and heroism has positively impacted my life and that of my friends and family. Having been given this gift of life has made me appreciative and eager to give back in any way possible. I am thankful for having received this award and wish to share it with both my wife Keesha and Scott. They truly made our story special!

Philip Rosario
Vancouver Chapter Coordinator
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. An important element of the PKD Foundation of Canada is to ensure that chapter support is available for those afflicted with PKD. These chapters focus on five key areas:

1. Support
2. Education
3. Awareness
4. Advocacy and
5. Local Fundraising

We currently have five chapters, including: Toronto (ON), Ottawa (ON), Hamilton (ON) Vancouver (BC), Corner Brook (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

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 2013 included:

- Living Kidney Donation and the Importance of Sharing your Story
- Understanding Polycystic Liver Disease;
- What’s New in PKD Research;
- Ethical Controversies in Kidney Donation and Transplantation;
- Kidney Nutrition Essentials & Today’s Trends
- Aneurysms and PKD
- Potential Therapies for 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 and transplant recipients, Chief Nephrologists and a Senior Fellow in Organ and Transplantation Ethics.
Chapter Updates

As an integral part of our mission, PKD Foundation of Canada chapters continue to strengthen their educational and advocacy initiatives through a variety of support meetings, social meet-ups, fundraising campaigns and community events.

The newly launched Vancouver Chapter has been doing an excellent job at increasing the visibility of PKD in the Greater Vancouver Area and hosted four educational meetings over 2013! In May, the Vancouver Chapter, along with members of the local media and political community, enjoyed a well attended Chapter Launch Party & Fundraiser to kick things off with a bang!

The Ottawa Chapter Coordinator stepped down during the year. Members in the local area remain dedicated to promoting PKD on a local level, and continue to be engaged from a fundraising perspective. We continue to seek an Ottawa chapter coordinator to help lead our dedicated volunteers.

Both our Toronto and Hamilton Chapters continue to host six educational support group meetings per year, with record attendance growth. Over this past year, each chapter welcomed a variety of medical professionals with an interest in PKD to speak with their members.
I had never heard of polycystic kidney disease until I was diagnosed with it about 12 years ago. Our third child was about a year old when I noticed some lumps in my stomach and that my waistline was getting bigger. I asked the doctor about the lumps and she agreed that something didn’t feel right. She sent me for an ultrasound immediately. At this appointment, I learned that both of my kidneys and liver were covered with cysts. I was referred to a nephrologist and diagnosed with PKD.

The worst part of this disease for me is the fact that it’s genetic. Our three children each had a 50% of inheriting PKD. My parents do not have it, which means I mutated the gene myself. This happens in about 10-15% of PKD patients.

I never really felt sorry for myself and know there is always someone worse off, but I didn’t like the fact that there was no treatment or cure. I hated the thought that my children could inherit PKD from me, so I decided to take action. I was also frustrated that no one had heard of this disease and I wanted to raise awareness of PKD and money that would go directly to PKD research.”
“I found out there was a PKD Foundation of Canada chapter in Toronto, and quickly discovered they were hosting their annual Walk for PKD that September (2004). I live in the small town of Vankleek Hill, ON and knew that my community would support my efforts. Our local paper ran an article about PKD and how I was trying to raise money to bring to the Toronto Walk for PKD. I held a bake sale; got Scotiabank to match my fundraising, and ended up bringing over $8,000 to Toronto. Over the past 10 years, we have raised just over $150,000 in Vankleek Hill!

I have always been a positive person and I am grateful and happy for the life I have. I am trying to pass this positive attitude onto my children.

I am so thankful that I learned about the PKD Foundation of Canada and am so happy to see it growing with more chapters and volunteers! Keep positive and keep smiling. We will find a cure!”

Cheri Barton, Vankleek Hill Walk Coordinator
Fundraising The Walk for PKD

This past Fall, over 900 PKD patients, their families and friends participated in the PKD Foundation of Canada’s signature fundraising campaign, the Walk for PKD and generated over $173,000 in donations! This is a 76% increase from 2012’s efforts. This event provides the backdrop for the single largest congregation of the PKD community in all of Canada and helps to spark added attention from the media and general public.

With this money and funds raised from past campaigns, we have been able to dramatically increase research here in Canada; bringing researchers closer to discovering a treatment for PKD. Without your support, this wouldn’t have been possible.

Many thanks to all of our dedicated volunteer Walk and Chapter Coordinators and their volunteer committees, our generous corporate and in-kind sponsors, as well as every participant who helped make this our most successful fundraising campaign to date.
The PKD Foundation of Canada was privileged to have the support of many great corporate sponsors this year. 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 2013, Otsuka Pharmaceutical Co. Ltd. became our first **DIAMOND LEVEL CORPORATE SPONSOR**; contributing $20,000 to the Walk for PKD campaign! Additionally, they joined the Toronto Walk for PKD with a team of 50+ attendees to participate in the day’s festivities.

**Quality Cheese Inc.** partnered with our Walk for PKD campaign as a **GOLD LEVEL CORPORATE SPONSOR**; donating $3,000 to our signature fundraising event. This family-operated business has been a longstanding advocate for the PKD Foundation of Canada and we are most thankful for their continued support and generosity.

We extend our utmost gratitude to both Otsuka Pharmaceutical Co. Ltd. and Quality Cheese Inc. for aligning themselves with the PKD Foundation of Canada and helping to make an incredibly positive impact in the local PKD community.
Comparative Contributions

* 2010 fundraising values include Ottawa Chapter fundraising events which did not take place over 2011, 2012, and 2013.
* 2011 fundraising values include the one-time Richmond Hill Mayoral Golf Tournament revenues which were $40,000.
A total of $51,632.18 (staff salary, EI and CPP) has been allocated into areas where the E.D’s time and attention has been focused.

*The above pie chart excludes net effect of HST refunds related to prior periods collected in current year.
A Heartfelt Thank You to Our Donors & Volunteers!

2013 proved to be the PKD Foundation of Canada’s most prosperous year to date. Great strides were taken to further strengthen our front-line initiatives – the promotion of research, advocacy, education, support and awareness – as we worked to accomplish both our financial and operational goals.

Once again, the PKD community’s support was the backbone of our success, generating record-setting attendances at both fundraising and educational events throughout the year. As a volunteer-driven organization, we rely on this vital support to advance our various programs and initiatives on an annual basis. Our dedicated and generous donors, partnered with our local chapters and Walk for PKD campaign have helped to shine a spotlight on polycystic kidney disease and the avenues in which the PKD Foundation of Canada can assist one on their journey.

From all of us here at the PKD Foundation of Canada, we thank you for your commitment to improving the quality of life for those living with PKD and for the continued funding of critical Canadian research into a treatment of this disease. Your personal efforts are positively impacting the lives of thousands of Canadians and millions of people around the world!