

The PKD Foundation of Canada 2011 Annual Report



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From the Chairman

Dear Donors,

In 2010, shortly after the national registration of the Polycystic Kidney Disease Foundation of Canada, I humbly took the reins as Chairman of the Board of Directors from Doug Robertson. The tremendous contributions Doug has made for the organization make it impossible to fill his shoes, but I hope to continue the exceptional organizational growth that began under his leadership. After 17 years of service, we are glad Doug remains an invaluable resource as an active board member.

After over a year in the role of Chairman, I am committed to maintaining the organizational momentum towards creating a comprehensive Canadian network of support groups. Our Chapters not only increase awareness and help us fund valuable world-class PKD research, but they are also the heart of our organization. The PKDFOC continues to be one of the most open and transparent charities of its size and I am especially proud of our strong dedication to be fully accountable to our donors!

Most importantly, 2011 brought some notable successes! An active new Chapter in Hamilton-Guelph, the largest research grant in our history, a successful rebranding campaign and a wonderful golf tournament partnership, which raised \$40,000! I encourage you to read the details of these fantastic accomplishments in this report.

I look forward to the exciting expansion ahead and helping to support even more Canadians in the PKD Community!

Sincerely,

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



From the Executive Director

Once again, this year was a record-setter for the PKD Foundation of Canada! With the continued support of our committed volunteers and generous donors, financial recognition and partnerships from numerous outside organizations and new Chapters launching across the country, it is no surprise we reached new peaks in both fundraising and awareness efforts on a national level.

This year, the PKDFOC added two new Chapters and one Walk for PKD event to its roster: The Hamilton-Guelph Chapter, inclusive of the Guelph Walk for PKD and an Autosomal Recessive Polycystic Kidney Disease (ARPKD) Chapter; benefitting those afflicted with ARPKD on a national level. Each of these initiatives made terrific strides in their first year; garnering a great deal of media attention, Chapter involvement and fundraising support.

Also this year, the PKDFOC was selected as one of the 2011 charitable recipients for the prestigious Town of Richmond Hill's Mayoral Golf Tournament; providing the Foundation with \$40,000 and invaluable publicity and awareness in the York Region. This was an incredible honour for the PKDFOC and a huge thanks goes out to Mayor Dave Barrow and his entire committee for supporting our organization in this capacity.

Our 2011 grant award to Dr. Marie Trudel, totalling \$89,400 over two years, is extremely exciting and very promising for the PKD Community! The work of Dr. Trudel and her team at the Clinical Research Institute of Montreal shows incredible potential and I am thrilled that the PKDFOC can support her research in this capacity.

Here's to 2012 and what will no doubt be another banner year for the PKDFOC and the Canadian PKD Community!

Sincerely Yours,

Jeffrey Robertson
Executive Director, PKD Foundation of Canada



The Organization

Polycystic Kidney Disease Foundation of Canada (formerly Polycystic Kidney Disease Research Society of Canada)

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Mission Statement

The mission of 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

Our vision is that **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 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.

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 its inception in 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

Eva Higgison joined the Board as Treasurer in July of 2009. Eva brings more than 9 years experience working with financial statements in multiple organizations of various sizes and financial activities. Eva previously worked closely with the Foundation as a Toronto Chapter volunteer prior to taking her current role.

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 three 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.

Rebranding

In 2011, the Foundation incorporated and began operating under its new name, the PKD Foundation of Canada. By incorporating nationally, the Foundation is better suited to expand and serve all Canadians affected by PKD.



*For Research in
Polycystic Kidney Disease*

The rebranding as the PKD Foundation of Canada aligns the Foundation with our American counterpart, the PKD Foundation, which provides the PKD Foundation of Canada with name recognition while simultaneously reducing branding costs by allowing for collaboration on educational and promotional materials.

We at the Foundation are ecstatic about our new look, and believe the transition will increase the positive impact the PKD Foundation of Canada can provide to those affected by PKD.

As an independent Canadian charity, we look forward to continuing the promotion of our front-line mission under this new name and image.

2011 Grant Recipient

The PKDFOC was proud to award a two year research grant at \$44,700/year (\$89,400 total) to Dr. Marie Trudel. Dr. Trudel is a Professor at the University of Montreal and an Associate Member of the Department of Medicine, Division of Experimental Medicine.

2011 marked the most competitive field of grant proposals in our history, with the largest number of grant applications we have ever seen. Dr. Trudel's grant was chosen by the PKDFOC Board of Directors after our independent Scientific Advisory Committee deemed it as providing the best Canadian clinical research value for the funds. It is our hope this research will bring us one step closer to finding a cure for PKD!

We are thrilled to see the amount of PKD research being conducted in Canada. With your support, we hope to continue funding world-class projects in the future.



Dr. Marie Trudel, Institute de Recherches Cliniques de Montreal (Clinical Research Institute of Montreal), in association with the University of Montreal.

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, PQ	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.	\$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, PQ	In vivo analysis of ADPKD pathologies for development of therapies.	\$44.7K
2012	Grant	Dr. Marie Trudel, PhD	Clinical Research Institute of Montreal	Montreal, PQ	In vivo analysis of ADPKD pathologies for development of therapies.	\$44.7K

Support Meetings & Chapter Growth

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 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 five chapters including: Toronto (ON), Ottawa (ON), Hamilton Guelph (ON), Cornerbrook (NL) and the ARPKD specific Chapter.

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

Support Meetings & Chapter Growth

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.

A major part of our local Chapter initiatives are the bi-monthly support group meetings. These are volunteer-driven educational events that help members better manage their disease by providing them with insightful information.

Topics discussed over the course of 2011 included:

- Current PKD therapies and clinical trials;
- Understanding Dialysis;
- Transplantation and living kidney donation;
- Understanding loss and managing grief;
- Hot topics in nutrition
- Autosomal Recessive PKD
- Clinical research updates

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

New Hamilton Chapter Coordinator



"Diagnosed in 2004 when I was living alone overseas, I felt dazed by the news and at a loss for what to do... The first in my family to learn that I had inherited and carried this incurable disease, a sense of loss and resignation followed me like a shadow. So when I returned to Toronto and discovered the Toronto Walk for PKD, I immediately signed up. For me, it was a source of information, comfort and gave me something I could actively do towards finding therapies and / or a cure for PKD. That in itself made me feel good.

And helping others makes me feel even better! As the Hamilton Chapter Coordinator since 2011, my aim is to raise awareness about PKD in the region and offer support to patients, their families and friends in the community. There is still progress to be made in helping people understand and cope with PKD, and I hope we can be there for people who have been dealing with PKD on their own for some time, and for those who are newly diagnosed alike. In the process, our Chapter helps raise funds for Canadian PKD research! Our inaugural Hamilton-Guelph Walk for PKD attracted the attention of a City Councillor, the media and raised an impressive amount of money! Step by step, together, we are making a difference."

- Shiona Mackenzie-Morrison, Hamilton Chapter Coordinator

New Hamilton-Guelph Walk Coordinator

"Back in 1997, my father-in-law was diagnosed with PKD. At that time, I had no idea what PKD was... It sounds crazy looking back, but we never knew about the Kidney Foundation of Canada, let alone the PKD Foundation of Canada; as we didn't seek help outside the family.

It wasn't until 2009 when Jim, my father-in-law, passed away that I got involved with the KFOC. I started with putting together a team in the KFOC Walk, but I wanted to do more! I decided to throw a Launch Party and as I was researching guest speakers for the event, I found the PKDFOC and Jeff Robertson. I invited Jeff to come speak and help create awareness for the PKDFOC, and the rest seems like history.

Last August, my husband was diagnosed with PKD and the support and education provided by the Hamilton Chapter has been of great help to me in understanding this disease. I look back on where we were 3 years ago and it amazes me how far the PKDFOC has come. It is an honour to be involved with an organization that has such a passionate, dedicated and understanding leadership team. Just thinking about the awareness we have created in such a short period of time is humbling. Over the past 3 years, we have launched a Hamilton-Guelph Chapter and have started an Annual Walk for PKD event that raised over \$5,000 in our first year. I can't fathom the success we will have in the future and the difference I know we are going to make!"

- Carrie Manson, Hamilton-Guelph Walk for PKD Coordinator



Public Awareness

With a focus on raising awareness of Polycystic Kidney Disease and the PKDFOC, Executive Director Jeff Robertson and PKDFOC volunteers were guests on a wide-range of Rogers *daytime* programs across southern Ontario; including Guelph, Mississauga, Toronto and the York Region.

In total, 10 interviews were given, re-airing 27 times, touching on topics such as National Kidney Month, World Kidney Day, the Walk for PKD, the importance of organ and tissue donation and of course the means of support the PKDFOC provides those in the PKD Community.



2011 Helene Kenigsberg Award of Excellence

Over the past number of years, Rogers Communications, and their staff at *daytime* specifically, have proven themselves to be terrific partners in the promotion of PKD awareness and local PKDFOC initiatives; discussing upcoming educational events and fundraisers, World Kidney Day and National Kidney Month, as well as sharing the personal stories of many PKDFOC volunteers.

This year's panel of judges, comprising of the PKDFOC Board of Directors and last year's award recipients, Mrs. Valen Keefer and Mr. Dennis McCloskey (*My Favorite American*), felt no entity had exemplified the dedication to PKD awareness and the PKDFOC mission, like Rogers *daytime* had this past year, and deemed it highly deserving to issue the 2011 Helene Kenigsberg Award of Excellence to them collectively.



On behalf of the entire PKD Foundation of Canada, we wish to thank Rogers and Rogers *daytime* for their support in raising public awareness of Polycystic Kidney Disease, resources provided to those affected by the PKDFOC, and how the public can become involved in the fight to end PKD!

Public Awareness of Polycystic Kidney Disease

As part of March's National Kidney Month and World Kidney Day (March 4th, 2011), Executive Director Jeff Robertson sat down with Lifetime's Pauline Chan, to discuss Polycystic Kidney Disease as part of her health segment on CTV's 6 o'clock news. This segment was picked up by various news stations across the country; providing invaluable awareness for both the PKD Community and the PKDFOC.

A very special thank you goes out to Dr. York Pei from Toronto General Hospital, for his involvement in this interview, and to Pauline Chan and her colleagues at CTV for all of their help in getting this story on the air!



Public Awareness (continued)

For the second year in a row, the PKDFOC was given the opportunity to participate in the Hamilton Spring and Fall Home and Garden show. The generous donation of in-kind booth space provided by show organizers, Continuum Productions Inc., provided the Foundation with the opportunity to meet many individuals affected by PKD and raise awareness among the 35,000+ attendees over the two events!

Events of this nature are wonderful avenues to share with those in attendance the importance of PKD research and support, organ donation and transplantation awareness, and the support provided by PKD chapters to those afflicted with Polycystic Kidney Disease.



Chapter Updates

The Foundation is now operating as a national organization under the PKD Foundation of Canada name. This change in branding and organizational jurisdiction has positioned us to connect with more members of the Canadian PKD Community and to be better equipped to provide them with the support of our front-line missions.

Both our Toronto and Hamilton-Guelph Chapters continue to carry out bi-monthly educational support group meetings, and recorded attendance growth throughout the year.

Corner Brook Chapter Coordinator Nina Young, leading the only established PKDFOC east coast chapter to date, has garnered a significant television and print media exposure to raise awareness of PKD and the PKDFOC.

The Foundation was actively searching for new volunteer leadership for the Ottawa Chapter in 2011. During this period, members remained active and dedicated in their fundraising and advocacy efforts, and their support of the 2011 Vankleek Hill Walk for PKD.

The Foundation is currently examining how best to expand into the western regions of Canada; as these are untapped resources of both PKD support and advocacy.

The Foundation will focus on continued support and development of existing PKD chapters efforts to raise awareness, fundraising, and support on a local level to those affected with PKD.

Fundraising

The 2011 Walk for PKD events were great successes, raising nearly \$73,000, an astonishing 28% over last year!

Already we have seen incredible results from the newly established Hamilton-Guelph Chapter, and this year's First Annual Guelph Walk for PKD was no exception! On Saturday, September 10th, with the sun shining overhead, 50+ people met at the beautiful Riverside Park to Walk for PKD! Friends and family of the local PKD Community were joined by Mr. Todd J. Dennis, City Councillor - Ward 6, who addressed the crowd during the ribbon cutting ceremony; as well as some highly enthusiastic folks from Money Direct, who sponsored the post-Walk BBQ! Thanks to the tireless efforts of Walk Coordinator, Carrie Manson and Chapter Coordinator, Shiona Mackenzie-Morrison, along with the commitment and passion of each Walker and their generous donors, the 1st Annual Guelph Walk for PKD raised \$5,000! A huge round of applause goes out to all who were involved in this inaugural event, and we look forward to seeing this Chapter's continued growth lead us to an even more successful 2nd Annual Walk for PKD!



Fundraising (continued)

In June of 2011, the PKDFOC was selected as one of two benefitting charities of choice by the Town of Richmond Hill, to participate in their prestigious 18th Annual Mayoral Golf Tournament. This event brought together both political figures and local professionals from the Town of Richmond Hill who felt compelled to make a positive impact in the local community.

Most importantly the event was a huge success and raised \$40,000 for the PKDFOC! These funds directly support our front-line mission to promote Canadian research into a treatment and cure for PKD, as well as the continued strengthening of educational and support initiatives for the PKD Community on a national level!



L – Town of Richmond Hill Mayor, Mr. Dave Barrow getting ready to hit the links.

Fundraising (continued)

A very special thank you to Mayor Dave Barrow from the Town of Richmond Hill, and to his dedicated staff who helped to provide invaluable awareness for the PKDFOC during this highly successful fundraising campaign!



Fundraising (continued)

This year, the Toronto Walk for PKD once again partnered with Boston Pizza – Yonge & Eglinton for their 10th Annual Toronto Walk for PKD Launch Party! In addition to providing a wonderful venue to host the event, Boston Pizza – Yonge and Eglinton generously joined as a **Gold Level Corporate Sponsor!** Through the Toronto Chapter's Launch Party fundraising efforts and Boston Pizza – Yonge and Eglinton's most generous match-funding, those in attendance raised over \$6,000 in support of the Toronto Walk for PKD!

A big thank you to franchise owner, Michelle Savoy, and the staff of Boston Pizza – Yonge and Eglinton, for aligning themselves with the PKDFOC and helping to make an incredibly positive impact in the local PKD Community.



**Here to make
you happy.™**



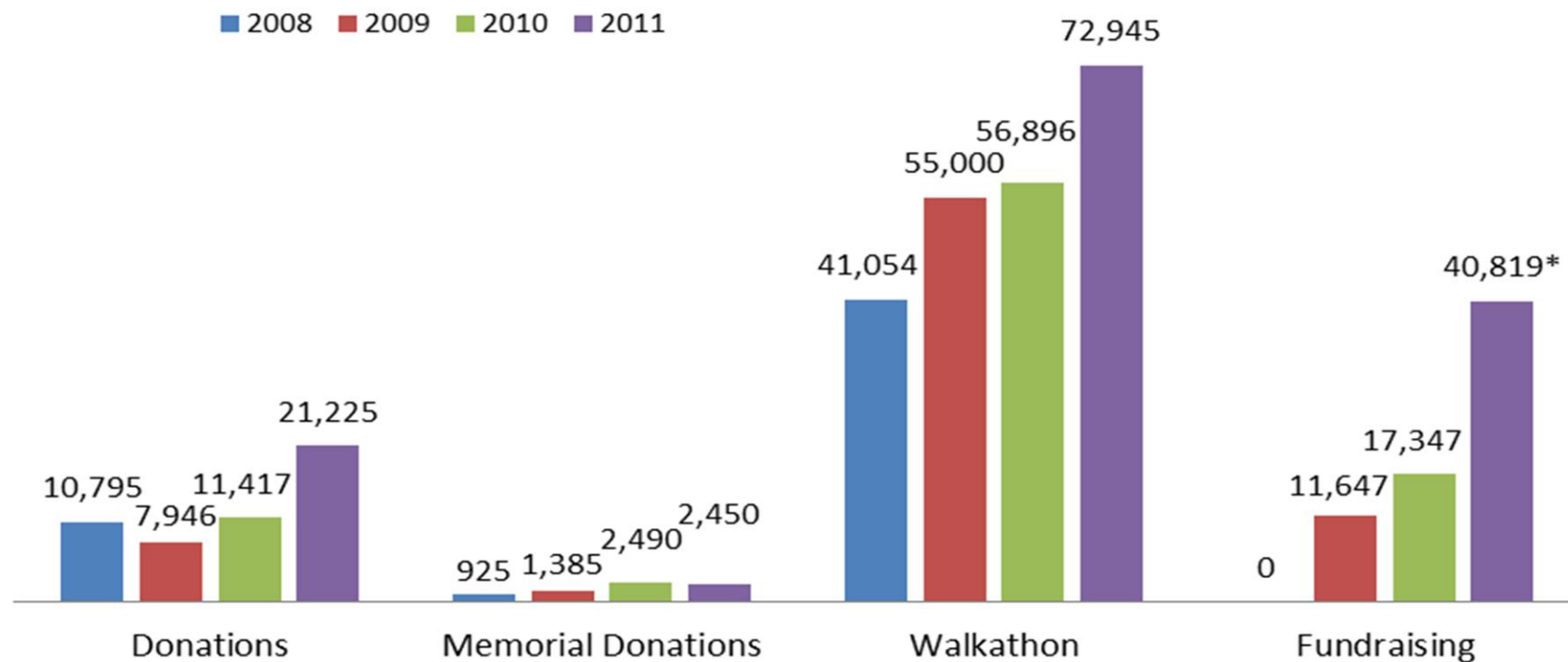
A Heartfelt Thank-You to Our Donors!

2011 was an impressive year for the PKD Foundation of Canada, as we exhibited substantial national growth on an organizational level. These steps forward allow the PKDFOC to continue providing the calibre of support Canadians affected by PKD have come to expect from us.

These accomplishments could not be met without the continued support of our generous donors, the passionate and dedicated volunteers we have working with us from coast to coast, and the efforts put forth by our Executive Director. Because of you, we are able move closer towards our vision that *no one suffers the full effects of Polycystic Kidney Disease*.

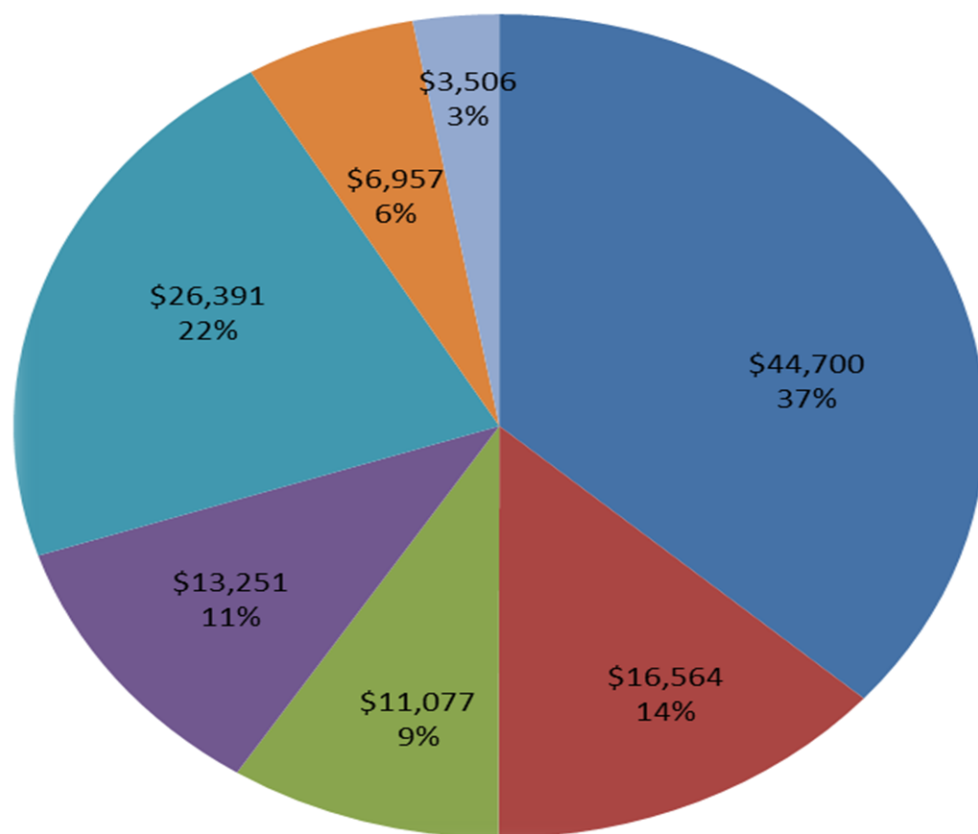


Comparative Contributions



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

2011 Expenses



■ Grant Awarded

■ Member Service and Education - Support Meetings, Webinars, PKD Phoneline, Newsletters

■ Fundraising/Walkathon - Costs associated with the events

■ Chapter Management - Establishing / training and ongoing support of Chapter groups

■ Foundation Growth and Development - Website development and upkeep, conference attendance, public awareness initiatives

■ Public Awareness - PKD brochure development & distribution, media contact (TV and print)

■ Legal and Insurance