

Celebrating Our 2009 Legislative Successes

The 2009 federal legislative session has come to a close and PKD Champions have many reasons to be excited. Now is a great time to reflect on our victories and successes, while at the same time it is time to ready ourselves for the hard work ahead. Thank you for all your support over the last year.

For the 19th year, Congress recognized the importance of PKD research at the National Institutes of Health (NIH). Congress highlighted the need for developing a public-private partnership to help establish PKD diagnostic and clinical treatment centers and also encouraged the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK) to convene a blue ribbon panel whose charge would be to develop a strategic plan outlining the future of PKD research. The NIH estimates that \$42 million will be spent on PKD research in 2010 - significantly more than the \$25.4 million spent in 2005. PKD researchers were also awarded more than \$2.3 million in funding from the federal stimulus package, which allocated an additional \$10 billion to NIH last winter.

In 2009, the Federal government moved forward with implementation of the Genetic Information Non-Discrimination Act (GINA). The intent of GINA is to protect individuals against discrimination by health insurance companies and employers on the basis of genetic information. Regulations implementing Title II, or the protections against employment discrimination, went into effect in late November. Title I regulations, which work to protect against discrimination in health insurance, were scheduled to go into effect in January 2010.

Beyond legislative priorities, the PKD Foundation's Advocacy Program is undergoing a few changes. We want to welcome Kim Cantor as the new National Director of Government Relations. Kim is based in Washington, DC and is very excited to work with PKD Champions to help advance legislation and policy that truly impacts the lives of people with PKD. In November, the Foundation re-launched the PKD Advocacy Network. Under the new Network, PKD Champions will continue to receive action alerts, notifying them when a priority issue needs their help on Capitol Hill. Furthermore, we encourage you to check out the new, streamlined and updated PKD advocacy website at www.pkdcure.org/advocacy.



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Learn more about
the PKD Foundation at
www.pkdcure.org

PKD Foundation

NEW YORK CITY CHAPTER

WINTER 2010



A Message From Your Coordinators: Brian & Susan

January 2010 began with a very successful chapter meeting! Lorrie Rome from the PKD Foundation provided us valuable information about the current impact of PKD Clinical Trials and PKD Studies. Thank You, Lorrie! It was great to see old friends and welcome new ones to the Chapter! This reinforced our New Year's wish to expand participation and increase awareness.

We have many exciting events planned for 2010, please join us in making PKD Awareness a priority for NYC. This is Your Chapter - Help us make it work for you. Stay connected!

Stay Informed Though E-mail and our Website!

With the rising costs of printing and postage, the New York City Chapter now does most of its communication through e-mail and the chapter website: www.pkdcure.org/newyorkcitychapter. To be sure you don't miss out on the latest information, e-mail us at: NewYorkCityChapter@pkdcure.org and ask to be added to the e-mail list. Don't forget to contact us when your e-mail address changes. If you thought you were on the list, but haven't received an e-mail for some time, check your spam controls or ask to be put on the list again. Be sure to include your complete name and address, or we will not be able to update your records, or add you to the database.

The PKD Foundation Receives Highest Ratings

Charity Navigator, America's largest evaluator of non-profit organizations, recently gave the PKD Foundation its 4 Star (highest) rating for efficiency. They wrote...**"Only 12% of the charities we rate have received at least 3 consecutive 4-star evaluations, indicating that the PKD Foundation consistently executes its mission in a fiscally-responsible way, and outperforms most other charities in America. This "exceptional" designation from Charity Navigator differentiates the PKD Foundation from its peers and demonstrates to the public it is worthy of their trust."**

A New Year and a New Location

In February, the PKD Foundation National Office's current building lease will expire and, in order to serve you better, we will be moving. The move comes at the perfect time as we have outgrown our current space. We are staying in Kansas City and are actually just moving down the street. Don't

worry. The move will not effect the daily operations of the PKD Foundation. Our new address will be 8330 Ward Parkway, 5th Floor, Kansas City, MO 64114 and we are currently in the process of putting our new address on all our printed materials. If you have any questions about the move, please email us at pkdcure@pkdcure.org.

CHAPTER INFORMATION

Chapter Coordinators:

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&

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The Walk for PKD...So Much To Celebrate!



Thank you to the 11,000+ participants who boldly stood up, stepped out and Walked for PKD this year in one of the 54 events that took place in 29 states. By sharing your stories and reaching out to friends, family, neighbors, co-workers and businesses, you have strengthened the PKD army in the fight for a treatment and a cure! Nationally we have raised nearly \$2.4 million – funds that will help fuel cutting-edge research (four therapies in clinical trials and counting), extraordinary patient

education (webinars you can engage in from the comfort of your home), life-changing advocacy efforts (lobbying the government to support the Immunosuppressive Drug Coverage for Kidney Transplant Patients) and more! Your passion is making progress possible... and this is why we walk.

A word from your local Walk for PKD Coordinator...

We are thrilled to report that the **Tri State Walk** had **546** participants come out to **Hudson River Park** (Pier 46 in Manhattan) on **October 25th** and help raise more than **\$250,000**. A simple idea wrapped around our Vision for a Cure, asking 20 people for \$20, allowed walkers to scale to new heights!

And special thanks to...

We would like to give a special thanks to our top **3 individual** fundraisers: **Amy Epstein \$54,387**, **Sara Arno \$26,345** and **Bill Brazell \$9,224**, as well as our top **3 teams**: **Team Odyssey \$54,387**, **The Producers of Long Island \$28,435** and **Team Sara \$26,500** for their tremendous dedication to make a difference.

We also want to thank **Coach Kevin Gilbride, Offensive Coordinator of the NY Giants and the 2009 TriState Walk for PKD Honorary Chairperson and our sponsors WPIX, Fresh 102.7, NYU/Langone Medical Center, The Rogosin Institute, Modell's, D'Arrigo, PopChips and Nestle Pure Life Water**, whose generous support helped underwrite our event expenses, allowing more of the funds raised to directly support the PKD Foundation mission.

Other notable contributors included:

- Kenny the Kidney (aka Bill Brazell) walked with everyone spreading awareness.
- Dr. G the CW / WPIX station weatherman helped cut the ribbon to start our Walk with excellent energy
- The Reilly Renals Team and their Captain, Renee Reilly, led a 55 member team that hails from New Jersey and Staten Island to raise \$10,074.00! Wow! The team also caught our eye with the Most Creative Team T-Shirt! "I'm Ciliar than you" blazoned on the backs of their navy T-shirts. It's never too early to start building a team for 2010!

Finally, we want to thank each of the volunteers who dedicated their time & talent on Walk Day and throughout the year to help make the **Tri State Walk** such a success. You are truly appreciated.



Ribbon Cutting with Mr. G



Penny Kids Dash with some of the younger generation team members of The Reilly Renals

New York City Chapter Calendar of Events

For more information on our events, visit us online at www.pkdcure.org/NewYorkCityChapter

March 1st and 2nd: United on the Hill

PKD Foundation Advocacy Event in Washington, DC. Your advocacy is vital to our efforts to find a treatment and cure for PKD. Registration is free. The PKD Foundation is offering a discounted room rate of \$150 per night at the Four Points Sheraton in DC. Online registration and additional information are available at www.pkdcure.org.

March 11th: World Kidney Day / New York City and New York State PKD Day

Join us for a celebration of PKD Day in NYC, an update about PKD research at NYU and recognition of all of the volunteers who helped make the 2009 Tri-State Walk such an extraordinary success! We are also in the process of asking for a proclamation for PKD Day in New York State and hope to hear soon. Stay tuned for more details!

March 13th: The NYC Metropolitan ADPKD/ARPKD Education and Awareness Seminar

Receive comprehensive updates about PKD from leading experts in their field, including:

- ARPKD: Beatrice Goilav, MD, FAAP, Attending, Pediatric Nephrology, The Children's Hospital at Montefiore, Assistant Professor of Pediatrics, Albert Einstein College of Medicine, Bronx, NY.
- Transplant Nephrologist: Alexander Gilbert, MD, Clinical Assistant Professor of Medicine, Division of Nephrology, NYU School of Medicine and NYU Langone Medical Center, NY, NY.
- Renal Nutrition: Zari B. Ginsburg, MS, RD, CDN, A-Z Nutrition, Manhasset, NY.
- Personal Experiences: Marvin McMillen, MD, Chief of Surgical Critical Care and Acute Care Surgery at Beth Israel Medical Center in Manhattan, Board Certified in General Surgery, Surgical Critical Care and Internal Medicine.

Saturday 9:30 am – 3:00 pm Check-in begins at 9:00 am

NYU / Langone Medical Center - Smilow Seminar Room

550 First Avenue (between 33rd and 34th streets), NYC

Light Lunch and Beverages will be served Registration Fee \$15.00 / person

Please register by March 11th – online at www.pkdcure.org/newyorkcitychapter; via e-mail at newyorkcitychapter@pkdcure.org or by calling Susan at 212-794-1258.

April: Chapter Meeting, with speaker

Date & location – to be determined

Join us as we review our chapter's first-quarter activities and plan for the rest of the year. At this meeting we will also work on our Spring Fundraiser.

May/June: Cocktails for a Cure Fundraiser

Date & location – to be determined

Plan on participating in this fantastic event, which will also feature raffles, silent and live auctions. All will be welcome and encouraged to attend.

July - December:

Stay connected with our Quarterly meetings in July and September. In August, consider attending the Annual Convention on PKD in San Diego or join us as we get Corporate Sponsors to Golf for a Cure. In October we will be back here for the TriState Walk for PKD.

Please join us as we forge ahead with a new tomorrow for the NYC Chapter!



2010 National Convention on PKD

Please join us August 6-8, 2010 in Sunny San Diego for the 2010 National Convention on PKD! The Convention will be held at the Sheraton San Diego Hotel and Marina. Online registration will open on March first. Mark your calendars now for this unique educational and social opportunity!