

## Support Your Chapter

The New York City Chapter wants to raise As Much Money Possible this year. Please help us kick-start the year with your donation. Every dollar makes a difference in the lives of 12.5 million people with PKD.

I would like to contribute under my name.  I would like to contribute in [Honor/Memory] of

Name: \_\_\_\_\_ Name: \_\_\_\_\_

Address: \_\_\_\_\_ Please send Acknowledgement to:

City/St/Zip: \_\_\_\_\_ Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Address: \_\_\_\_\_

E-mail: \_\_\_\_\_ City/St/Zip: \_\_\_\_\_

Phone: \_\_\_\_\_

E-mail: \_\_\_\_\_

Please mail donations to:

PKD Foundation

Attn: New York City Chapter

9221 Ward Parkway, Suite 400

Kansas City, MO 64114

If you would like to contribute via credit card please call 1-800-PKD-CURE and mention the New York City Chapter when you make your contribution.



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Kansas City, MO 64114

1-800-PKD-CURE  
[www.pkdcure.org](http://www.pkdcure.org)

Learn more about  
the PKD Foundation at  
[www.pkdcure.org](http://www.pkdcure.org)

## PKD Foundation

# NEW YORK CITY CHAPTER

SPRING 2009



## This is YOUR Chapter!

The New York City Chapter is taking great strides in 2009. We want to offer a variety of exciting events, meetings and educational opportunities. But to do this we need you! From helping to lead our education and support efforts, to something as simple as providing refreshments at meetings – there is something for everyone. This is YOUR Chapter and we want everyone to be a part of it. Get involved! Suggestions are especially welcome for Fundraisers and Social Events. Please contact us at [NewYorkCityChapter@pkdcure.org](mailto:NewYorkCityChapter@pkdcure.org) if you are interested in a volunteer job or in helping the New York City Chapter in some other way. Here are just a few of the volunteer jobs that we want to fill:

### 2008 by the Numbers

- 1 Educational Seminar
- 2 Booths at Health Fairs
- 1 Walk for PKD
- 1,000 hours worked by volunteers

More than \$132,000  
Raised at the TriState Walk and by the  
Chapter for Research and Education

Visit us online at [www.pkdcure.org/  
NewYorkCityChapter](http://www.pkdcure.org/NewYorkCityChapter) to see what we  
plan to do in 2009!

**VOLUNTEER TEAM** -- Recruitment Leader: Seek volunteers to participate in or lead chapter activities. Recruit volunteers through the local chapter, community organizations and web postings. Skills: Computer/Microsoft Office, communication, a positive attitude and the ability to respond to volunteer inquiries in a timely manner.

**FUNDRAISING TEAM** -- Monetary Sponsorship Leader: Solicit & secure monetary sponsorship for chapter events. Submit and follow-up on sponsorship proposals and coordinate sponsor agreements. Skills: Professional, writing, effective business contact, organization. Other jobs on this Team include In-Kind Sponsorship Leader & Logistics Leader.

**PUBLIC RELATIONS/AWARENESS TEAM** -- Public Outreach Leader: Cultivate public awareness of PKD and promote chapter events. Skills: knowledge and awareness of community groups/ individuals with potential to increase PKD & chapter awareness; ability to network with them. Other jobs on this Team include Media Leader & Online Leader.

## PKD Webinars

The PKD Foundation is taking education to the next level! In October of 2008 the PKD Foundation unveiled its quarterly webinar program to rave reviews. The program offers everyone the chance to hear from top PKD experts on topics important to you, all from the comfort of your own home. Two webinars have already been presented and can be viewed anytime by visiting [www.pkdcure.org](http://www.pkdcure.org). While you are there, take a moment and sign-up for the next live webinar, which will take place on March 17 with Dr. Montgomery.

### CHAPTER INFORMATION

Chapter Coordinator:

Susan Caplan

212-794-1258

[NewYorkCityChapter@pkdcure.org](mailto:NewYorkCityChapter@pkdcure.org)  
[www.pkdcure.org/NewYorkCityChapter](http://www.pkdcure.org/NewYorkCityChapter)

## The 2008 Walk for PKD...Much To Be Thankful For



Between September 13th and November 9th, fifty-nine different Walk for PKD events took place in 32 different states. Nationally, the Walk for PKD put approximately \$2.8 million into the pipeline for critical research funding, patient education and support. Locally, the Tri State Walk for PKD raised approximately \$132,000.00. There is much to celebrate and be thankful for.

The positive effects of the Walk for PKD go well beyond Walk Day. Because of funds raised through the walk, people newly diagnosed will be able to find the PKD Foundation on the web and lessen their fears by arming themselves with information. Because of funds raised through the Walk for PKD, we will continue to lobby on Capitol Hill for issues important to the PKD population. Because of funds raised, in part through the Walk for PKD, clinical trials are taking place and may someday soon lead to a treatment. Because people with PKD need a voice, we walk. A cure for polycystic kidney disease is our finish line, so until there is a treatment and ultimately a cure, we walk.

The Tri State Walk for PKD was a Huge Success! This year we were organized by EventWorks. Rich and Chris Mauch and their staff did a monumental job of securing permits, setting up the sound stage and contacting sponsors. The New York City, Long Island and New Jersey Chapters all joined in and participated to hold ONE WALK. The TriState Walk took place at Pier 46. It was a windy and chilly morning, but the great views of the Hudson River inspired us. Jim Watkins from the CW Television Network was our Master of Ceremonies. The Rogosin Institute (Dr. Blumenfeld) and Langone/NYU Medical Center (Drs. Skolnik and Barash) were sponsors. The balloon arches were so colorful against the sky, as well as our PKD TriState T-Shirts! The food and beverages were yummy and refreshing. All the Children loved the Penny Kids Dash....Our own, Kenny the Kidney (aka Bill Brazell- [www.kennythekidney.com](http://www.kennythekidney.com)) walked with us, too! It is never too early to plan ahead for next year's TriState WALK !!! Form your team/start fundraising .....for 2009.

## Your Advocacy Can Help End PKD

By getting involved, your efforts can make a vital difference in the lives of 600,000 Americans suffering from PKD and millions more in future generations of their families. Need proof? The work of our PKD Champions helped lead to a remarkable victory in 2008—the passage and signing into law of the Genetic Information Non-Discrimination Act (GINA), which Senator Edward Kennedy (D-MA) called “the first major civil rights legislation of the 21st century.”

That's amazing progress in a short period of time. Our work, however, is far from over. A lack of adequate federal funding of PKD research threatens the momentum in this field. PKD patients and families still face challenges to a better quality of life, such as inadequate Medicare coverage to pay for expensive anti-rejection drugs after a kidney transplant. PKD costs Americans more than \$2 billion a year in Medicare costs related to dialysis, transplantation and related therapies.

What's the next step? Simple: Get involved. Your advocacy can make all the difference in our mission to find a treatment and cure for PKD. Visit [www.pkdadvocacy.org](http://www.pkdadvocacy.org) to start making a difference!

## National Convention on PKD - Empower Yourself

Don't miss the 2009 National Convention on PKD. Join us this summer in Chicago, IL on June 26 - 28, at the Double Tree Hotel Chicago - Oak Brook. Registration is now open for this great educational event. To register please go to [www.pkdcure.org](http://www.pkdcure.org) and click on the 2009 National Convention logo.

*“I quickly realized that these strangers all understood and cared about the disease that has harmed my family for generations. That realization led to the joy of making new friends and realizing that my fate is not sealed. Please come and join me at this year's National Convention on PKD, and see that you are also not alone in your battle with PKD.”*

- 2008 National Convention on PKD Attendee

For more information about this great opportunity for PKD patients and families visit [www.pkdcure.org](http://www.pkdcure.org).



## New York City Chapter Calendar of Events

For more information, please visit us online at [www.pkdcure.org/NewYorkCityChapter](http://www.pkdcure.org/NewYorkCityChapter)

### March 2009

National Kidney Month

### March 2nd - 3rd, 2009

Champions on the Hill Event  
Washington, D.C.

### March 19, 2009

Chapter Meeting - 6:00 p.m.  
Grand Central Station Dining Concourse...in  
front of Junior's Restaurant

**RSVP: by March 18th** to Susan Caplan at  
[NewYorkCityChapter@pkdcure.org](mailto:NewYorkCityChapter@pkdcure.org) or by  
phone at 212-794-1258.

### Spring 2009

Educational Seminar

Date, location and other details - TBD

Visit our chapter page at [www.pkdcure.org/newyorkcity](http://www.pkdcure.org/newyorkcity) or contact Susan Caplan at [NewYorkCityChapter@pkdcure.org](mailto:NewYorkCityChapter@pkdcure.org) or 212-794-1258 for updates about this seminar.

### June 26th - 28th, 2009

National Convention 2009  
Chicago, IL

### Fall 2009

Walk for PKD

## Email Reminders

Would you like to receive updates directly to your in-box with the latest Chapter and PKD Foundation information? Send your name, mailing address and e-mail address to [volunteers@pkdcure.org](mailto:volunteers@pkdcure.org) and we will add you to the PKD Foundation and New York City Chapter e-mail lists. Then look for updates about meetings, events, volunteer opportunities, clinical trials, webinars and much more.