

Support Your Chapter

The New Jersey Chapter has a fundraising goal of \$80,000 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 Jersey 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 Jersey Chapter when you make your contribution.



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Kansas City, MO 64114

1-800-PKD-CURE
www.pkdcure.org

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

PKD Foundation

NEW JERSEY CHAPTER

SPRING 2009



This is YOUR Chapter!

The New Jersey Chapter is taking great strides in 2009. We want to bring a variety of exciting events, meetings and educational opportunities to the area. But to do this we need your help! We have a wide assortment of volunteer positions in our Chapter. From helping to lead our education and support efforts, to something as simple as providing refreshments at our meetings – there is something for everyone. Being involved in the Chapter is a great way to support your community, as well as a way to play a big part in the fight against PKD! This is YOUR Chapter and we want everyone to be a part of it. Contact Barb Seidman or Peggy Street at NewJerseyChapter@pkdcure.org or 732-274-0850 (Barb) or 201-650-9959 (Peggy) to find out how you can start making a difference in

your Chapter today! Like the rest of you, Barb and Peggy are volunteers and work during the day. When calling either of us, please leave voicemail messages and we WILL get back with you.

2008 by the Numbers

- 1 Educational Seminars
- 2 Chapter Meetings
- 1 Fundraiser
- 2 Walk for PKD Events
- More than 500 Hours Worked by Volunteers

More than \$161,000
Raised for Research and
Education at the Central NJ &
TriState Walks for PKD, plus
additional NJ Chapter activities.

Connect With Others at a Chapter Meeting

While PKD affects whole families, sometimes it can leave you feeling all alone – but you are NOT alone. Let us prove that to you at our upcoming Chapter Meetings. Chapter Meetings are a great time to connect with other PKD patients and families, learn about the latest PKD research from a variety of speakers and find out how you can make a difference in the lives of 12.5 million people – and your own family.

The New Jersey Chapter holds meetings in various locations and even holds some meetings via telephone conference calls. Right now we're looking into setting up a private chat room for monthly online meetings. We also participate in an annual education seminar, along with four other chapters. Please see our calendar of events or visit our chapter webpage at www.pkdcure.org/NewJersey for more information about our Chapter meetings. We hope to see you there!

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. 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 Coordinators:

Barb Seidman
&
Peggy Street

NewJerseyChapter@pkdcure.org
www.pkdcure.org/NewJerseyChapter

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 nearly \$3 million into the pipeline for critical research funding and for patient education and support. Locally, the Central Jersey Walk for PKD raised more than \$29,000 and the TriState Walk for PKD raised approximately \$132,000. 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 treatments. Because people with PKD need we walk. A cure for polycystic kidney disease is our finish line, so until there is a treatment and ultimately a cure, we walk.



Barb Seidman, Stacey Trzesinski and Peggy Street at the Central Jersey Walk for PKD

Email Reminders

Would you like to receive updates directly to your in-box on the latest Chapter and PKD Foundation information? Send your name, mailing address and e-mail address to volunteers@pkdcure.org or call 1-800-PKD-CURE and we will add you to the PKD Foundation and New Jersey Chapter e-mail lists. Then look for updates about meetings, events and volunteer opportunities, clinical trials, webinars and much more.

Please do Barb & Peggy a favor and let us know of any changes to your mail and e-mail addresses. Mail sent to old addresses that aren't up-to-date means that many people are not receiving mailings and e-mails that include important information about PKD, the PKD Foundation and the New Jersey Chapter. Also, if we only have your business e-mail address, you may not be receiving important information in a timely manner – or even at all.

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.

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 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 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.

New Jersey Chapter Calendar of Events

For more information, please visit us online at www.pkdcure.org/NewJerseyChapter

March 2009
National Kidney Month

March 2nd - 3rd, 2009
Champions on the Hill Event
Washington, D.C.

Spring 2009
PKD Educational Seminar
Details TBD Please check our webpage for updates.

May 16, 2009
NJ Chapter Bowl-a-thon Fund Raiser
Details TBD. For further information, to attend or to volunteer, e-mail NewJerseychapter@pkdcure.org or call Peggy at 201-650-9959.

June 26th - 28th, 2009
National Convention 2009
Chicago, IL

Fall 2009
Walk for PKD
Check us out online for specific dates

2008 Holiday Brunch...A Perfect Way to End The Year



On December 14th many of us enjoyed a delicious brunch at Old Man Rafferty's in New Brunswick. It was wonderful to have time to socialize with each other during the holidays. We hope you can join us next year.