

Clinical Trials Need Participants

We have quite a few members currently involved in clinical studies to help understand treatments for PKD. Both the HALT Study and the Tempo ¾ (Tolvaptan) Trials are still recruiting patients so they can reach the targeted enrollment. Please consider participating. If you are interested, find out more about qualifications and details in our area by using the resources below:

HALT Study:

- Beth Israel Deaconess Medical Center
Boston, Massachusetts, United States, 02215
Contact: Bonnie Maxwell, R.N.
866-650-1815; bmaxwel1@bidmc.harvard.edu
- Tufts University-New England Medical Center
Boston, Massachusetts, United States, 02111
Contact: Peachy Simon, BSN, RN, CNN
866-846-2735; psimon@tufts-nemc.org

Tempo ¾ Study: Tolvaptan Trials

Tempo Study Information Line for the U.S. - 866-712-5837

- The Rogosin Institute: NY, NY - John D Blumenfeld, M.D.
- Nephrology Assoc. of Westchester: Hawthorne, NY
Stephen Adler, M.D.
- Columbia University Medical Center: NY, NY
Jai Radhakrishnan, M.D.



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

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

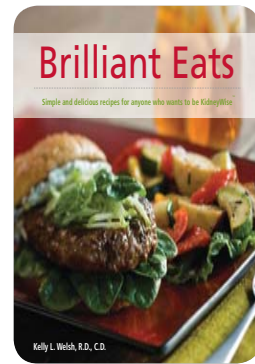


- Is your mailing information correct?
- Have you received more than one mailing?
- Would you like to be removed from our Chapter mailing list?
- Would you like to be added to our e-mail list?

We are striving to serve you better and keep our database clean. To report an issue or to update your information please e-mail volunteers@pkdcure.org and let us know how we can better serve you. Thanks!

Brilliant Eats Cookbook

For PKD patients and families everywhere, high blood pressure and the risk of kidney failure are scary realities. For years, your calls and e-mails to the PKD Foundation have focused on diet and nutrition because the Kidney Diet is among the most complex diets to follow. Therefore, the PKD Foundation has published its very first cookbook, called Brilliant Eats.



The book was written by renal dietician and PKD patient Kelly Welsh, RD, CD and reviewed by Poonhar Poon, MS, RD, LDN, and Anne-Marie Desai, RD, as well as renal dieticians and nephrologists at the Mayo Clinic and Tufts-New England Medical Center.

The cookbook features recipes for each stage of the kidney-disease experience. It also features nutritional guidelines and vital nutrition information any PKD patient will want to have on hand. All of the Brilliant Eats recipes are quick, easy and taste good. Order your copy at www.pkdcure.org.

PKD Foundation

LONG ISLAND CHAPTER

SUMMER 2008



A Message of Hope

From Gillian Kolodny, Chapter Coordinator

Welcome! Our local chapter of the Polycystic Kidney Disease Foundation is comprised of many dedicated individuals volunteering to make a difference. The good news is that we may be closer than ever before.

This continues to be a time of exciting advances on both the national and local levels of the PKD Foundation. With help from volunteers across the country, we have advocated for a change and the Genetic Information Non-Discrimination Act (GINA) was signed into law. Both the HALT Study and Tolvaptan clinical trials are underway and unlocking clues about PKD. We need to keep up the pace! In fact, there are still ways people can participate. Read more about this in the Advocacy and Clinical Trials sections of the newsletter. Just remember, every bit helps.

On a local level, we continue to have a strong support group and member base that believes in spreading awareness about PKD by holding monthly meetings, educational seminars, family days and even producing a weekly television show that you can see on Cablevision's Public Access television. Check us out! Our current airtime is Wednesday mornings at 9:30 AM. We are always looking for new members. There are thousands of people in the Long Island area who have PKD. Come share your stories, get support and volunteer for a great cause. Together, I do believe we can make a difference!

We've Got a NEW Name

For some years now, we've been known as the Greater New York Chapter. While we cover a "great" area, the name does not easily identify where our members are from. We've received calls from folks that were not aware there even is a chapter here on Long Island. Since helping others find support and educating the community about PKD is so important, we've decided that our name needs to better represent WHO we are.

Did you know our chapter covers all of Suffolk County, Nassau County and Queens? We will now be known as the Long Island Chapter. Please bear with us as we change our name. Our new email address will be longislandchapter@pkdcure.org. We invite you to come meet us and join the fun! Please e-mail if you wish to be included on our local chapter e-mail list and we'll see to it that you receive all the necessary details and meeting minutes so you are best informed. In the event that you would like to be removed from future PKD Foundation e-mails or mailings, please let us know and we'll make that change.

Chapter Events

Below is an outline of our meetings, which happen on the THIRD Thursday of every month at 7:00 PM. You'll notice that we continue to switch between our Nassau and Suffolk locations to best meet the needs of our members. Please visit www.pkdcure.org and click on "Connect Locally". This will lead you to our Long Island Chapter site. There you will find driving directions for meetings and other details.

- 7:00 p.m. -September 18, 2008- Sachem Public Library
- 7:00 p.m. -October 16, 2008- Manhasset: Waldbaum's Dialysis Center
- 7:00 p.m. -November 20, 2008- Sachem Public Library
- 7:00 p.m. -January 15, 2009 - Sachem Public Library
- 7:00 p.m. -February 19, 2009- Manhasset: Waldbaum's Dialysis Center

PLUS

- o December 2008 - Pot Luck Holiday Party- details to be announced
- o March 2009-NYC Metropolitan Area ADPKD/ARPKD Education & Awareness Seminar; details and speakers to be announced

CHAPTER INFORMATION

Chapter Coordinator:

Gillian Kolodny

516-382-0902

LongislandChapter@pkdcure.org

www.pkdcure.org/Long

IslandChapter

Help Wanted: Volunteers!

Our "Volunteer Army" is always looking for more like-minded friends to join the cause. There is no time like the present to raise your hand and get involved. PKD chapters are always receiving money from people who have put together a craft fair, bake sale, gotten their company to sponsor a casual day or one of many other fun projects.

There are also people out there who have stepped up and decided they have the time and resources to host a major event or who want to work with a local organization to host a larger event. Many non-profit organizations have started connecting with local sororities, fraternities and other social organizations to put on a large event. Maybe you aren't ready to host an event yourself, but you still want to help out and get involved. Well, we can definitely use your help, too. No job is too big or small! Here are a few of the volunteer jobs we currently have available:

- Walk for PKD- Volunteers needed on October 18th for day of event. This could include greeters, check-in, food & beverage, route marshals and education and advocacy table volunteers.
- 4th Annual NYC Educational Seminar Organizer. This March event is a joint effort with three other chapters and help is needed to recruit sponsors and organize the day of event.

If you are interested, have contacts with businesses that could be potential corporate sponsors, have an idea for an event that you would like to put together or know of a company, house of worship or social group that would like to support our chapter, please contact us at longislandchapter@pkdcure.org.

Coming Soon...

The biggest chapter events of the season are coming and you want to be there!

PKD-Long Island Family Fun Day Saturday, September 20, 2008 10AM-1PM

We will meet back at Holtsville Ecology Site and Park Preserve for the 5th year and celebrate the end of summer together. Remember, this year we will not walk on this date, but ask that you join us in Manhattan for the TriState Walk for PKD on October 18th. Much like our beloved Holiday Pot Luck, this will be a time to enjoy family and spend time with other members. We will have all the things you've come to love about this day, like the bagel breakfast, kids games, Chinese Auction and a picnic lunch. There's also the petting zoo, a favorite for all ages! We hope to see you! Please RSVP by September 12th to longislandchapter@pkdcure.org to let us know if you can make it.

Advocacy - Make a Difference!

Get involved with supporting legislation that benefits PKD patients. Congress and the President recently passed the GINA bill because of people like you! While the PKD Foundation is pleased, there is still regulatory work on the bill that needs to be completed before the law takes full effect. Regulations, or "regs," will need to be written by several agencies before GINA takes effect, and that process will take from 12 to 18 months. The PKD Foundation and other advocacy organizations will monitor this process to ensure the regs follow the intent of the law, as passed. PKD patients should be aware that, until this process is finished, GINA will not be in effect. In the meantime, individuals may have questions about GINA or about getting tested for PKD or participating in clinical trials. The PKD Foundation is working on compiling information and frequently asked questions to help individuals understand the protections offered by GINA. This information will be available soon on www.pkdcure.org.

Sign up for Action Alerts! We need as many people as possible to contact their Senators and Representatives so that legislation that relates to PKD can be passed. Go to www.pkdcure.org for more information on how to help.

Hope Square

Hope Square is a brand new online community for PKD patients and others affected by PKD – just like MySpace, Facebook and others. Users will be able to create personal profiles, write blogs, upload videos and meet other people who have PKD. You'll also be able to join groups and forums, which will allow you to connect with others in the PKD community. Finding support and sharing with others is an important part of living with PKD. Hope Square will give you the opportunity to connect with people who have those common experiences, and find hope, support and advice. Look for updates soon as we work on developing this exciting, new online community!



TriState Walk for PKD

As many of you have heard from conversations with members and e-mails, Long Island, New York City and Jersey City have joined forces to become the TriState Walk for PKD. The TriState Walk for PKD is gaining momentum...be part of the team! This is the only walk that will be held in our area this year, so don't miss out! Please let us know if you will be able to make it. Call the PKD-L.I. Hotline at 631-363-6184 or e-mail longislandchapter@pkdcure.org. We may try to coordinate carpools if enough people are interested.

- Saturday, October 18, 2008 (Rain or Shine)
- Hudson River Park @ Pier 46, New York, NY
- Check-In: 9:00 AM
- Walk Begins: 10:30 AM
- Route: Choice of 2 or 4 miles, along the scenic Hudson River

Register Today! No Registration Fee!

www.pkdcure.org 1-877-PKD-WALK

Penny Kid's Dash

Remember kids can fundraise, too! Before the Walk starts, kids 12 and under can participate in a fun run across the finish line.

Exciting New Day of Incentives

Raise \$100 on or before the Walk and receive an official TriState Walk for PKD T-shirt at check-in. If you raise \$300 on or before the Walk, you will receive an official PKD soft-sided cooler at the event

Form a Team!

Become a Team Captain and receive a special Team Captain hat prior to the Walk. To receive a Team Captain Kit, call 1-877-PKD-WALK or e-mail TriStateWalk@pkdcure.org. Each Team that raises \$6,000 or more will receive an LCD TV! Awards will be given to the Top Teams in the following categories: ADPKD Corporate; ARPKD Corporate; ADPKD Friends & Family & ARPKD Friends & Family.

Congratulations to the Long Island Chapter!

Six short years ago, our chapter decided to begin anew. We had a dream of putting together a Walk for PKD that would help raise funds and awareness for PKD. At the time, our "dream team" had little understanding of what it took to put on such a venture, but we had passion about what they were fighting for. The Walk was a success and has been growing ever since. Each year, members like you share new ideas and improvements are made. Most importantly, the chapter has endured and added many new teammates along the way. Together, we have done so much! It is a pleasure to share with you the following accomplishments that have happened in our chapter this year:

- At the PKD National Convention in Dallas this June, our chapter was given a prestigious honor. We received "The Gift of One Another"-- awarded to one chapter annually for providing outstanding support to their members by helping each other cope with PKD, offering encouragement and supporting each other with personal time and effort. This is one of the five core chapter missions and we are truly thankful for the recognition. Support has always been the glue that has held us together all these years. PKD's chronic nature can often take its toll on our health. Our members have proved time and again that they are there for one another and this family atmosphere is what is treasured most.
- The 2007 Walk for PKD at Holtsville Park raised over \$45,000. While this was an impressive increase from the previous year, it also marked our chapter reaching our goal of being one of the top 20 Walk for PKD events in the country! We welcomed many teams whose donations made all the difference like "The Gang Team", "Helen's Helpers", "Steve's PKD Team", "The Champions Club", "The Caracciolos", "Team Watson", "Team of Hope", "The Kuerner Team", "Remembering Tom", "Ohlsen Family and Friends", "NYCFD Engine 82 Ladder 31", "Kidney Connection", "Grandma Rose's Team", "Bubby Chave's Walkers", "Team Warshaw", "warnken Walkers" and "Angelo's Angels". With the help of team winners like the folks at "Pear Staffing" and the "Ciniglio Team", we pushed our fundraising goals to new heights. Congrats to Joey Ciniglio for being the highest fundraiser for our youth members. Your efforts were amazing!
- "The Producers" raised over \$20,000 and became the third highest team in the nation last year, due in large part to our second year Walk for PKD Visionary, Ira Ginsburg. Not only was he the top fundraiser for our chapter, he was the 7th highest in the nation! Ira was honored by the PKD Foundation for his successful fundraising abilities for the past two years. We're lucky to have such a dedicated member among us.