

Stay Informed Through E-mail and our Website!

With the rising costs of printing and postage, the Long Island Chapter now does most of its communication through e-mail and the chapter website: www.pkdcure.org/longislandchapter. To be sure you don't miss out on the latest information, e-mail longislandchapter@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.

ADPKD Clinical Database Project Underway

The ADPKD Clinical Database is a collaboration which includes the major players involved in getting drugs approved to treat ADPKD: The Food & Drug Administration, pharmaceutical industry and clinicians with years of data collected from PKD patients and the PKD Foundation.

The years of accumulated clinical data gathered in observational studies at three major sites will provide the foundation of the database. New data from the CRISP & HALT studies, as well as other current clinical trials, will be added to the database in the future. This is a situation where more is better. Once it is all gathered in one spot, the data can be analyzed and will provide a natural history of the disease over time. Changes over time in various clinical measurements, such as blood pressure and total kidney volume, and more subjective factors, such as quality of life and pain, will be documented. This information will be used in the design of future clinical trials.

The first phase of the database project began July 1, 2009. This first year will focus on data elements in existing registries and those to be included in the new database. The first face-to-face meeting of major participants was scheduled for August 27-28 in Washington, D.C.



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PKD Foundation

LONG ISLAND CHAPTER

SUMMER 2009



A Message From Your Coordinator - Gillian Kolodny

I hope everyone has enjoyed the summer! The PKD Foundation's Long Island Chapter has been busy. On a local level, we continue to have a strong support group and member base that believes in helping others cope with the emotional aspects of the disease. Our meetings are a place where we share our stories, listen and truly care. Being that members represent all stages of PKD, from initial diagnosis to ESRD and dialysis and pre/post transplantation, conversations and connections take place within the group and on an individual basis as well. It is also important to us to spread information and awareness about PKD. We continue to host educational seminars, family events and we've even produced a PKD television show that you can see on Cablevision's Public Access. It is always terrific to see new faces and meet new friends also affected by PKD. You may have seen members at recent events, such as our monthly support meetings, the NYC Educational Seminar on June 6th or at our Family Fun Brunch at the Holtsville Ecology Park on July 25th. We welcome you to come join us on this journey. Our Long Island Chapter is comprised of many dedicated individuals volunteering to make a difference. The good news is that we may be closer to a treatment and cure than ever before and we must keep up the pace! In fact, we are always in need of volunteers and there are many ways people can participate. Just remember, every bit helps.

Current Things We Are Working On Are:

- Choosing topics for our upcoming 2010 PKD-Long Island Lecture Series. These will take place at our monthly meetings and allow for more targeted "roundtable discussions" on topics that you want to learn more about. Some suggestions brought up by our membership are: Holistic Healing and Living Naturally, Transplantation, ESRD and Dialysis, Insurance and Medicare, Positive Attitudes and the Psychology of PKD. Please contact us at longislandchapter@pkdcure.org so that your vote is counted!

- Another chapter fund-raising idea is to gather recipes for a cookbook of Long Island Chapter family favorites. This would be a collection of recipes submitted by our chapter members that could possibly be sold as a chapter cookbook. It would not be a book focused on the PKD diet, but more of just a fun collection of recipes. We are at the beginning stages of this, so feel free to send us your best creations, whether they are kidney-friendly or not. If you have a recipe that you would like to submit, please e-mail it to longislandchapter@pkdcure.org.

We are always looking for new members! There are thousands of people in the Long Island/Queens area who have PKD. Come share your stories and get support from those that welcome and accept you. Together, I do believe we can make a difference!

Chapter Co-Coordinator Needed

We need someone who is eager to jump right in and help manage the team, along with Gillian Kolodny, current Chapter Coordinator! You don't need experience, but you need a dedication to the PKD Foundation mission, leadership/organizational skills and a desire to help recruit and motivate others. Provided to the Co-Coordinator: training, staff support, materials, Coordinator Handbook and more. If interested, please contact Gillian at LongIslandChapter@pkdcure.org.

CHAPTER INFORMATION

Chapter Coordinator:
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www.pkdcure.org/LongIslandChapter

Volunteering Makes Our Chapter Stronger

The Long Island Chapter is bringing 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. 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 Foundation 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 couple volunteer jobs we currently have available:

- **TriState Walk for PKD** - Volunteers needed on October 25th for day of event. This could include greeters, check-in, food & beverage, route marshals and education and advocacy table volunteers.
- **6th Annual NYC Educational Seminar Organizer.** This event is a joint effort with four other chapters and help is needed to recruit sponsors and organize the day of event, which typically takes place in the spring.

If you are interested in any of the above, 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 so we can help you get started on the right path. It is that easy to start making a difference!

PKD Clinical Trials

The clinical trials part of the Foundation's website will see some major changes by the end of the summer. The new design will group the trials by drug being tested and show how far along in the testing and approval process each one is. Although approval cannot come too soon for those with ADPKD, it is encouraging to see how far along in the process many of the studies are.

Here are some updates:

- Dr. Andreas Serra and colleagues recently published the preliminary safety and tolerability results of the first six months of treatment with sirolimus in 50 patients. They found that treatment of ADPKD patients with the drug at a low dose is safe and does not cause loss of protein in the urine or does not impair GFR. Efficacy results, or whether or not the drug slows or stops disease progression, will be published once the clinical trial is completed.
- A new clinical trial testing rapamycin in ADPKD has begun at Yale University. This study is designed to determine whether rapamycin is a safe and effective treatment for patients with ADPKD. Total kidney volume and cyst volume will be measured. Blood and urine samples will be collected to evaluate changes in biomarkers thought to be associated with the disease.
- Two recently-released scientific publications report on drugs that have been found to be effective in mouse models of advanced cystic disease. Both rapamycin and R568, a drug that affects calcium levels, were found to slow disease progression. Although it is still early in the process, it is hopeful to see research efforts directed to this segment of ADPKD patients.

Come Join the Fun with Long Island Chapter Members!

TriState Walk for PKD

For the second year we will be part of the TriState Walk for PKD, along with the New York City and Jersey City Walks. Come be part of the team! This is the only Walk that will be held in our area this year, so don't miss out! The PKD Foundation is focused on rallying everyone to get involved and make an even bigger impact in the fight against PKD. This year, we are asking all Walk participants to ask 20 friends for \$20, and join our 20/20 Vision. Can it really be that easy? Truthfully, it is. Keeping it simple and remembering that when we focus on fundraising, the results are clear – we will get one step closer to a cure for PKD.

Ready to find out just how simple it is for you? Visit us online at www.pkdcure.org/tristatewalk and sign on to Walk; registration is free. Then start asking! Join us in 2009 as we set our sights on a cure with 20/20 Vision; though the biggest reward is knowing that you have made a difference, there are great prizes to say thanks. Raise \$100 and earn a T-shirt; raise \$200 or more and also receive a great prize!

October 25, 2009 (Rain or Shine)

Hudson River Park's Pier 46

Charles Street and West Street (West Side Highway)
New York, NY 10014

Registration/Check-in Begins: 9:00 AM

Walk Begins: 10:30 AM

Route: Choice of two or four miles, along the scenic Hudson River.

Register: online at www.pkdcure.org/tristatewalk

Email: TriStateWalk@pkdcure.org

Other Chapter Events - Mark Your Calendars!

Below is an outline of our chapter meetings, which happen on the 3rd 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 all our members. Please visit: www.pkdcure.org/longislandchapter for additional information.

- 7:00 PM -September 17, 2009- Sachem Public Library
- 7:00 PM -October 15, 2009- Manhasset: Waldbaum's Dialysis Center
- 7:00 PM -November 19, 2009- Sachem Public Library
- December 2009 Annual Pot Luck Holiday Party- details to be announced
- 7:00 PM -January 21, 2010 - Sachem Public Library
- 7:00 PM -February 18, 2010- Manhasset: Waldbaum's Dialysis Center

Scientific Programs Update

Germino named as NIDDK Deputy Director

Greg Germino, M.D., was named Deputy Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in May. Dr. Germino is a familiar name to the PKD Foundation – he is an expert in ADPKD, has served on the PKD Foundation's Scientific Advisory Committee, spoken at PKD National Conventions and received the Lillian Jean Kaplan International Prize for Advancement in the Understanding of Polycystic Kidney Disease in 2005. While continuing to pursue his own research program, Dr. Germino will now help oversee an annual budget of \$1.9 billion and a staff of 630 scientists, physician-scientists and administrators at NIDDK, part of the National Institutes of Health.

