

## NEW Online PKD Learning Center

The PKD Foundation recently launched the PKD Learning Center online. It can be accessed from the [www.pkdcure.org](http://www.pkdcure.org) homepage. The PKD Learning Center is a compilation of many of the tools we use to help broaden understanding of this disease. This comes in the form of written material, webinars and a new addition - video vignettes. You will see we have tried to segment all these pieces to address the various ways people process information. Additionally, we have provided a "stages" module to help people pinpoint information pertinent to where they might be in their journey with PKD. Eventually, we'll also look to provide the same full blown treatment for ARPKD.

## 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

# CONNECTICUT CHAPTER

SUMMER 2009



## A Message From Your Chapter Coordinator - JoAnn Lemons

Once again I am excited about the growth in the Connecticut Chapter, including the addition of a new Walk Coordinator, Jaime Lazarus. As you read this newsletter, Jaime will share information about this year's new Walk activities. Recently I attended the National Convention on PKD in Chicago and met with several Chapter Coordinators from around the world. The common need in all chapters is to have more participation in the planning of the chapter activities. At our November 2008 Education Seminar, many people expressed interest in volunteering to help with the newsletter, social activities, awareness, education or other areas. Please contact me and we can find an opportunity to meet or talk. I have materials available to assist in the planning and implementation of these programs.

As a result of our 2008 fund raising events, again this year, the Connecticut Chapter was able to fund a research grant - for Dorien Peters, PhD at Leiden University Medical Center. Way to go Connecticut! It's great to know that we are part of a worldwide effort to find a treatment and cure for PKD. Research is so important in finding a treatment and cure and that requires money, which entails fundraising. Perhaps there is an idea you would like to try. Please see the article in this newsletter about how YOU can hold a chapter fundraiser.

Fall is always a busy time of year for our Connecticut Chapter. The Education seminar last year was well attended and this year we are again working with Yale University. The Seminar will be held November 14, 2009 at the Yale Medical School TAC building. Dr. Ted Steinman, from Boston, will discuss pain management and offer possible solutions for pain associated with PKD. Check the Connecticut web page for updates about this great educational opportunity. Read this newsletter to also find updates on scientific research, as well as other important information, and remember that the PKD Foundation web page ([www.pkdcure.org](http://www.pkdcure.org)) will soon include information from the June Convention sessions. Looking forward to seeing and hearing from you; I know I will see many of you at this October's Connecticut Walk.

## Stay Informed Though Email and our Website!

With the rising cost of printing and postage, The Connecticut Chapter now does most of its communication through e-mail and the chapter website: [www.pkdcure.org/connecticut](http://www.pkdcure.org/connecticut). To be sure you don't miss out on the latest information, email the Connecticut Chapter at [ConnecticutChapter@pkdcure.org](mailto:ConnecticutChapter@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.

### CHAPTER INFORMATION

Chapter Coordinator:  
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## Walk For PKD: 20/20 Vision – A Clear View of a Cure!



In just eight short years, the Walk for PKD has become the signature event for funding programs of research, advocacy, education, support and awareness for polycystic kidney disease. Though the fundraising is truly impressive – more than \$12 million in eight years - we have just begun to scratch the surface. Here in New Haven we raised \$43,000 last year and are aiming for \$50,000 in 2009. 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. Do you know 20 people you could ask for \$20 each to support your efforts? If all 14,000+ walkers last year had done just that we would have raised more than \$5.6 million in 2008.

The Connecticut Walk for PKD will take place Saturday, October 3rd at the beautiful Light House Point Park in New Haven. We are planning on having plenty of fun-filled family events, including the Penny Kid's Dash, live entertainment, a caricature artist and much more! As we raise funds and raise hope on our path to finding a cure, here in New Haven, if we have all walkers focused on the 20/20 Vision we can achieve our highest Walk yet! Ready to find out just how simple it is for you? Visit us online at [www.pkdcure.org/ConnecticutWalk](http://www.pkdcure.org/ConnecticutWalk) and register 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!

## Liver Cysts in ADPKD

### Dr. Neera Dahl, Yale University School of Medicine

Most patients with ADPKD also have cysts within the liver. Although liver function remains intact in ADPKD, the increasing liver volume due to the increase in cysts growth can lead to complications. Sometimes cysts can grow large enough to cause compression of the stomach or small intestines. Patients may report a sensation of early satiety, or feeling full, after only eating small amounts, or of heartburn or gastroesophageal reflux disease (GERD) when acid from the stomach backs up into the esophagus. Patients may also have abdominal pain from the enlarging cysts.

*Women may have more complications from liver cysts, as massive cysts are seen more commonly in women, particularly women who have previously had children. Patients may also find the enlarging cysts disfiguring, with an appearance of an enlarged upper abdomen out of proportion to the remainder of the body.*

Treatment of complications of the liver cysts will depend on the severity of the problem. Some patients may adjust by eating smaller, more frequent meals and by avoiding foods and conditions that will worsen GERD. Others will consider surgical interventions, such as cyst decompression or removal of part of the liver (partial hepatectomy), for relief. Some patients with massive liver enlargement from cysts may consider liver transplantation.

Two clinical trials are evaluating the safety and efficacy of somatostatin analogs in treating polycystic liver disease. Somatostatin is a hormone that regulates the activity of other hormones. Octreotide and lanreotide are synthetic analogs of somatostatin and will be used in these studies. The octreotide trial is based in the Mayo Clinic in Rochester, MN and is currently recruiting patients.

## Plan Your Own Event

There are many people who support the PKD Foundation and want to get involved in their local chapter. We understand it's not always possible to attend meetings or other chapter activities. However, you can still participate by holding a fundraiser in your town and then donating the proceeds through your chapter. Your fundraiser will play a major part in funding more PKD research, awareness, education and support!

### Who should consider doing this?

Anyone who has a good fundraising idea, wants to devote some time to planning/promoting it and will work through the Chapter Coordinator. The fundraiser possibilities are endless. You name it and one of our chapters has probably done something similar.

### What type of fund raiser do you hold?

Think about something you already know, like to do, would be fun and think others would attend. Examples: A person who is a regular golfer may want to hold a golf tournament. Someone who likes to throw parties, may have a dinner party/fundraiser. People who belong to clubs or other organizations may consider planning events that would appeal to members of those groups.

### A few things that will make a fund raiser more successful include:

- Notify your Chapter Coordinator about your idea as soon as possible. Although you will take the lead on this event, working through the chapter will ensure that more people know about it, PKD Foundation procedures are followed and other chapter supporters possibly help you make it happen.
- Plan well ahead – it takes time to plan and promote any type of event; so plan at least a few months ahead for the best results.
- Keep expenses low – no more than 10-15% of your expected revenue; otherwise, you will spend more than it is worth to hold the event. Get as much donated as possible.
- Hold it in a safe, central location with ample parking or other transportation options.
- Get others involved in helping to plan and execute the event.
- Promote, Promote, Promote; PKD Foundation staff can help with this as long as you plan ahead.

## Connecticut Chapter Calendar of Events

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



### Connecticut Walk for PKD Site Meeting:

Saturday, September 12th at 1:00 p.m. at Lighthouse Point Park

### Connecticut Walk for PKD

Saturday, October 3rd at 11:00 a.m. Registration begins at 10:00 a.m.  
Lighthouse Point Park, New Haven, CT

### Connecticut Chapter Awareness Booth at NBC 30 Health & Wellness Festival

October 17 & 18, 2009 at Connecticut Convention Center: Hartford, CT

Volunteers Needed to Staff Connecticut Chapter Booth at the NBC 30 Health & Wellness Festival.

Volunteer Time Slots – 3 hrs (or longer, if you like) between 10 AM and 5 PM both days

**Please RSVP to JoAnn Lemons by October 12th** at [connecticutchapter@pkdcure.org](mailto:connecticutchapter@pkdcure.org) or (203) 469-9225.

### Connecticut Chapter Education Seminar:

Saturday, November 14th at 10:00 a.m.  
Yale Medical School/Tac Building

**RSVP by November 12th** to JoAnn Lemons at [connecticutchapter@pkdcure.org](mailto:connecticutchapter@pkdcure.org) or 203-469-9225.

