

## 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 is scheduled for August 27-28 in Washington, D.C.



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## PKD Foundation

# HUDSON VALLEY CHAPTER

SUMMER 2009



## A Word From Your Chapter Coordinator

I recently found a binder from the first PKD Foundation Conference I ever attended... in 1997. Following a kidney infection and my father's kidney transplant, I'd decided that I needed to do something about my PKD and so I went to the conference. The research update in that binder contains practically nothing... news about the genes which had been recently discovered, but nothing that could help me then. Today I take 4 little white pills every day; each pill full of hope. These little white pills might be Tolvaptan. And they might slow down the cysts that are eating up my kidneys! How exciting is that?! In 12 years time we've gone from "not much" to dozens of clinical trials, which offer real hope to those of us living with the ticking PKD time bomb. I am so grateful for the PKD Foundation and all it has done to promote research, advocate for us and give us hope. I am also glad that I made the decision a while back to get involved... for that has allowed me to find better doctors, make better decisions about my health and be on top of things like clinical trials. The days of "there is nothing you can do about it" are over... so **please**, make sure you are doing what you can to be involved and informed!

Heidi Cambareri, Chapter Coordinator: 914-953-1163 or [HudsonValleyChapter@pkdcure.org](mailto:HudsonValleyChapter@pkdcure.org)

### Way to Go Hudson Valley!

Once again the Hudson Valley Chapter was the recipient of several awards at the annual PKD Foundation Convention in Chicago in June. Hudson Valley was honored with the Best Political Awareness Award for consistently participating in PKD Foundation government relations activities (thank you to all who have lobbied on Capitol Hill, taken part in Action Alerts, etc!) and the Collaboration Award for our partnership with the Long Island, NYC, ARPKD and NJ chapters. In addition, it was announced that the Hudson Valley Chapter funded a research grant award to Carsten Bergmann, MD, PhD at the Aachen University of Technology. Congratulations to our Walk for PKD 2008 Visionary Award Recipients: Michele Karl (\$13,514), Kirsten Sclater-Booth (\$7,623), and Sam Friedlander (\$6,171) and our 2008 TeamFirst Award Recipients: Kirsten Sclater-Booth (Luke's Team raised \$16,375) and Michele Karl (Three Peas in a Pod raised \$13,871).

## ARPKD Families...Connected

For years now there are hundreds of walkers that come out on Walk for PKD day to honor the lives and memories of their loved ones with ARPKD. The 2009 Walk for PKD will be no different.

Last year alone the PKD Foundation had 66 teams registered as "Walking for ARPKD" at over 34 walk events raising more than \$202,000. Out of 32 teams recognized in the inaugural class of TeamFirst teams, 7 were ARPKD- designated teams. Joining on a local level or hosting your own "Virtual Walk" under the "Walking for ARPKD" designation is a great way to connect locally and nationally with other families affected by PKD, including those with ARPKD.

The Hudson Valley Walk has had the involvement of ARPKD teams since we started five years ago. Two of these incredible families have raised over half of our walk funds each year and helped our Chapter fund two ARPKD specific research grants! Come to the Hudson Valley Walk and meet Luke's Team and Three Peas in a Pod. They are inspirational families and teams. It's a fun and powerful way to do something positive to help support research, education and advocacy for PKD.

If you have questions about how your family can join or how you can get support year round, please contact Julia Roberts (404-731-8931) or Michele Karl (914-522-6193) or [arpkdchapter@pkdcure.org](mailto:arpkdchapter@pkdcure.org).

### 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 Bedford Hills we raised \$60,000 last year and are aiming for \$75,000 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. Here in the Hudson Valley if we had all walkers focused on 20/20 Vision we could achieve our highest walk yet – and that means doing the most yet for the fight against PKD. Ready to find out just how simple it is for yourself? Visit us online at [www.pkdcure.org/hudsonvalleywalk](http://www.pkdcure.org/hudsonvalleywalk) 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!

The Hudson Valley Walk will take place on Saturday, September 26th at the Bedford Hills Memorial Park in northern Westchester. Registration starts at 9am and we walk at 10am. All walkers are invited to enjoy a delicious lunch after the walk thanks to Shop Rite and other local businesses and restaurants. This is a great event for the whole family. The 2.5 mile walk is stroller friendly and there will be music compliments of NightLight DJs, face painting, a raffle and a silent auction. It's our biggest and most fun fundraiser of the year- don't miss it!

### Hudson Valley Chapter's Calendar of Events

For more information on our chapter meetings and events please visit us at [www.pkdcure.org/hudsonvalleychapter](http://www.pkdcure.org/hudsonvalleychapter)

#### September 2, 2009

7:00 PM

Walk for PKD planning meeting

Bedford Hills Community House

74 Main Street

Bedford Hills, NY

#### September 26, 2009

10:00 AM

Walk for PKD

Bedford Hills Memorial

Park

Check our webpage or your e-mail for information about a Chapter meeting with an informational guest speaker in October and a fundraiser/social event in November!

**In need of support?** Contact Sandy Grossman at [sandyg48@verizon.net](mailto:sandyg48@verizon.net) or 914-666-4073 for information on support meetings in our area.

**Interested in government advocacy?** Contact Sue Wang at [pkd\\_advocacyhudson@yahoo.com](mailto:pkd_advocacyhudson@yahoo.com) for more information.

## 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.

### Need Ideas?

Here are a few fundraisers that PKD Foundation Chapters have held: Golf Tournaments; Motorcycle Rides; Yard Sales, Bake Sales; Dinners/Cooking Demonstrations; Fashion Shows; Restaurant Fund Raiser (restaurants donate % of proceeds for that day); Silent Auctions; Parties – charge per person – promote through social networks; Holiday Book Wraps; Wine and Cheese Tastings; Local Sporting Team Events.

So, if you're ready – get in touch with your Chapter Coordinator. Discuss your idea. Then plan and hold your own fundraiser!

## Stay Informed Though Email and our Website!

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

