

Scientific Programs Update

ADPKD Clinical Database Project Unerway

The ADPKD Clinical Database is a collaboration which includes the major players involved in getting drugs approved to treat ADPKD. This impressive group includes: 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.

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. As an expert in ADPKD, he has served on the PKD Foundation's Scientific Advisory Committee, spoken at PKD National Conventions and received the Lillian Jean Kaplan International Prize for the 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.



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

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



PKD Foundation

PHOENIX CHAPTER

SUMMER 2009



A Letter From Your Coordinator!

Hello Phoenix Chapter members! Summer hit the valley rather early this year, so we're gearing up for some very cool and informative networking events at Whole Foods Market - with an even cooler Walk for PKD on October 11th, at DC Ranch Marketplace!

As always, we're seeking motivated individuals to help us increase PKD awareness. Our goal is to help the Foundation pave a path for a treatment (and ultimately a cure) for PKD, through advocacy, education, and fundraising. As your local Chapter, we also share a heartfelt desire to support all those diagnosed with PKD, through unity, hope, and compassion.

Connecting with your local chapter can be one of the most uplifting and empowering commitments you'll ever make. Just knowing that you're not alone on the path for a cure can be awe-inspiring. And, when you engage in activities with others, you can take your own personal journey to a far more powerful and compelling level!

Don't worry if you've never done anything like this before. (We were all rookies in the beginning). We simply want grow to be one of the most effective chapters in the country - and we need your help to get us there.

Make the first move today! Simply email PhoenixChapter@pkdcure.org with a subject line of: "Count Me In 4 Consideration!" (In the body of the email tell us about yourself, even if you don't have any idea of what you'd like to do). All you need to do is reach out to us, and we'll work with YOU to generate the best "fit" for your talents.

Stay Informed Though Email and our Website!

With the rising cost of printing and postage, The Phoenix Chapter now does most of its communication through email and the Chapter website: www.pkdcure.org/phoenixchapter. To be sure you don't miss out on the latest information, email Phoenix@pkdcure.org and ask to be added to the email list.

Don't forget to contact us when your email 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.**

Making Your Chapter Stronger

The Phoenix Chapter wants to continue to bring a variety of exciting events, meetings, and educational opportunities to the area. But to do this we need you to demonstrate that this is important to you by showing up! Low attendance can dramatically affect future opportunities. There's power in numbers. Show up and make a difference for all!

CHAPTER INFORMATION

Chapter Coordinator:

Risa Simon

480-575-9353

PhoenixChapter@pkdcure.org

www.pkdcure.org/

PhoenixChapterChapter

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



In just eight short years, the Walk for PKD has grown into the signature event for funding programs of research, advocacy, education, support, and awareness for polycystic kidney disease. Though the fundraising is truly impressive – with more than \$12 million raised in eight years - we have just begun to scratch the surface.

In Phoenix alone, we have raised more than \$220,000 to date (during our first three walk years) - and this year we're aiming for more than \$70,000!

With your help, we believe we can easily surpass this year's fundraising goal! The PKD Foundation is focused on rallying everyone to get involved and make an even bigger impact in the fight against PKD with our new 20/20 Vision.

20/20 Vision encourages all walk participants to ask 20 friends for \$20. It's just that simple! (Last year, if all 14,000+ walkers had done just that, we would have raised an additional 5.6 million in 2008!) 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're getting one step closer to a cure for PKD!

Do you know 20 people whom you could ask to donate \$20 each? Ready to find out just how easy it could be? Visit us online at www.pkdcure.org/phoenixwalk and register to walk; registration is free! Then all you need to do is start asking!

Raise \$100 and earn a T-shirt; raise \$200 or more and receive another prize! This year's Phoenix Walk, proudly presented by CBS 5 and DC Ranch Market Street, should prove to be our most popular ever!

And here's the cool news: **We've pushed our Walk date back to Sunday, October 11th with registration beginning at 8:00 a.m. and our start line ceremony at 9:00 a.m.** Following our 5K and one-mile walk, we will end up on the Plaza on Market Street for an entertaining and informative networking corporate expo, featuring booths by the PKD Foundation, Kidney Kinships 2 Live 4, Donor Network of Arizona, Fit City, Scottsdale HealthCare Noah Bus - and other great resources. We'll also have treats and bottled water – and doggie bowls for the pooches! Simply put, it will be fun for the whole family!

Join us this year as we set our sights on a cure with 20/20 Vision - though the biggest reward will be in knowing that your contributions made a difference!

ARPKD Families...Connected

Over the years, hundreds of walkers have come out on walk day to honor the lives and memories of their loved ones with ARPKD. The 2009 Walk for PKD will be no different. Last year 66 teams registered as a division "Walking for ARPKD" at over 34 walk events across the country, and successfully raised over \$202,000!

Joining in on a local level (or hosting your own "Virtual Walk" under the "Walking for ARPKD" designation) is a great way to connect with a larger ARPKD community. If you have questions about how your family can join an ARPKD group, or get ARPKD support year round, please contact Julia Roberts (404-731-8931) or Michele Karl (914-522-6193) or arpkdchapter@pkdcure.org.

NEW Online PKD Learning Center

The PKD Foundation recently launched the PKD Learning Center online. It can be accessed from the 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.

Clinical Trial Update

We will soon see some design improvements on the Foundation's website regarding clinical trials. The new layout will group the trials by drug being tested, and show how far along in the testing and approval process each one is. Although approval can not 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:

- **Sirolimus:** Dr. Andreas Serra and colleagues recently published the preliminary safety and tolerability results of the first 6 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.
- **Rapamycin:** 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.
- **Rapamycin and R568:** 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.

Plan Your Own Event

There are many people who support the PKD Foundation and want to get involved in their local chapter, but they can't always attend meetings or other chapter activities. Well, you can still participate by holding a fundraiser through your local chapter. Your fundraiser can play a major part in funding more PKD research, awareness, education, and support! Just email phoenixchapter@pkdcure.org to share your ideas and get approval to get started.

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.

What type of Fundraiser could you hold?

Think about activities that you enjoy and are already familiar with, and that other people might enjoy too. 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/wine tasting fundraiser. People who belong to clubs or other organizations may consider planning events that would appeal to members of those groups.

Fundraiser Checklist:

- 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 and that the PDK Foundation procedures are followed.
- Plan 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 execute the event
- Promote, Promote, Promote; (PKD Foundation staff can help when you plan ahead).

Got Fundraising?

Here are a few Chapter fundraising ideas which were successfully held over the years: Golf Tournaments; Motorcycle Rides; Yard Sales, Bake Sales; Dinners; Fashion Shows; Restaurant Fund Raiser (restaurants donate % of proceeds for that day); Silent Auctions; Parties – charge per person; Wine and Cheese Tastings.

So, if you're ready – get in touch with our Chapter by emailing: [phoenixchapter @pkdcure.org](mailto:phoenixchapter@pkdcure.org). It's just that easy!

