

# Your Advocacy Can Help End PKD

By getting involved, your efforts can make a vital difference in the lives of 600,000 Americans (including 11,000 Arizonians), and future generations of PKD. Need proof? The work of our PKD Champions helped lead to a remarkable victory in 2008—the passage and signing into law of the Genetic Information Non-Discrimination Act (GINA), which Senator Edward Kennedy (D-MA) called “the first major civil rights legislation of the 21st century.”

That’s amazing progress in a short period of time. Our work, however, is far from over. A lack of adequate federal funding of PKD research threatens the momentum in this field. PKD patients and families still face challenges to a better quality of life, such as inadequate Medicare coverage to pay for expensive anti-rejection drugs after a kidney transplant. PKD costs Americans more than \$2 billion a year in Medicare costs related to dialysis, transplantation and related therapies.

What’s the next step? Simple: Visit the Foundation’s website [www.pkdcure.org](http://www.pkdcure.org) and watch your incoming email for action alerts to ensure that you are up to date on the most current happenings. Be sure to take action when the Foundation encourages you to do so.

Kick-start your commitment - and let your voice be heard on the Organ Donation Clarification Act. Endorsed by the PKD Foundation, this ground-breaking bill suggests controlled incentives to increase living organ donation, as a means of addressing our country’s deplorable deceased organ shortage.

Currently, over 5,000 PKD patients are waiting for a kidney transplant with an average wait of five years for a diseased donor. Help us make a difference. Write you senators and ask them to support this Act. It just takes a moment of your time. Visit: [www.pkdadvocacy.org](http://www.pkdadvocacy.org) to learn more



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1-800-PKD-CURE  
[www.pkdcure.org](http://www.pkdcure.org)

Learn more about  
the PKD Foundation at  
[www.pkdcure.org](http://www.pkdcure.org)

## PKD Foundation

# PHOENIX CHAPTER

SPRING 2009



## This is YOUR Chapter!

The Phoenix Chapter is taking great strides in 2009. We want to bring 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 with fundraising and support efforts, to something as simple as providing refreshments at our meetings – there is something for everyone! Being involved in the Chapter is a great way to support your community and the PKD Foundation, while playing a big part in the fight against PKD!

### 2008 by the Numbers

- 4 Chapter Meetings
- 4 Fundraisers
- 1 Walk for PKD
- 3 PKD Awareness Booths
- 540 Volunteer Hours

More than \$67,580 Raised  
for Research and Education

Visit us online at [www.pkdcure.org/PhoenixChapter](http://www.pkdcure.org/PhoenixChapter) to see what we plan to do in 2009!

## Chapter Meeting Connections

Although PKD affects whole families, there are times that a PKD patient can feel all alone. This is what makes your connection to our Phoenix Chapter that much more appealing! In our supportive PKD community, our members never feel alone, because we all share similar circumstances. Our like-minded connection comes from our thirst for knowledge and our hope for a better tomorrow.

Chapter meetings empower members through supportive friendships and learning experiences. Last year our Chapter held some extraordinary educational sessions, which included a remarkable panel of living kidney donors & recipients, a naturopathic nutritionist, an interactive health and wellness forum, and a presentation on understanding living kidney donation and the donor recruitment process.

If you liked last year’s line up, you’re in for a real treat this year! **Mark your calendars for Saturday, March 28, 2009 at 9:00 a.m.** for our first Chapter meeting. It will be held at New Vision Center - Peace Room located at 9659 N. Hayden Road in Scottsdale, AZ 85258. Our special guest speaker will be Dr. Alejandro Morales, an AKDHC nephrologist, who will be speaking to us on “Living with PKD.” At an upcoming meeting we will also be hosting one of the valley’s most popular (and revered) nephrologists, Dr. Savas Petrides, for an open Q & A session.

## Exciting Member Happenings

Congratulations to our PKD kidney transplant recipients who received their new kidneys last year and are all doing remarkably well: Dean Benigno, Dave Sultana and Tom Fulcher.

The biggest acknowledgement goes to our brave living donors. If not for their selfless gift of human kindness, our loved ones might have spent many years on dialysis while waiting for a transplant. Be it through their direct donation or a paired donation chain, we salute our angels; Leigh Reynolds, Michelle Fulcher and Toni Sultana for giving their recipients renewed life.

### CHAPTER INFORMATION

Chapter Coordinator:

Risa Simon

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[PhoenixChapter@pkdcure.org](mailto:PhoenixChapter@pkdcure.org)

[www.pkdcure.org/PhoenixChapter](http://www.pkdcure.org/PhoenixChapter)

## Online Support

A great new way to connect with chapter members on a daily basis is through the new online support website, HopeSquare. HopeSquare is a social networking site, much like Facebook or Myspace; however, it is just for people affected by PKD and their loved ones. HopeSquare allows PKD patients to “meet” other patients and learn about their experiences through friendship and support, so no one has to ever feel alone.

Thanks to the work of Jenny Dennis and Teri Simon, we now have a group for PKD in Phoenix – so be sure to join in on these enlightened conversations! To join, simply go to: <http://hopesquare.org/>, create an account for yourself and join our group. The link to our support group is: <http://hopesquare.org/Groups/tabid/94/forumid/42/scope/Threads/Default.aspx>.

## PKD Webinars

The PKD Foundation is taking education to the next level! In October of 2008 the PKD Foundation unveiled its quarterly webinar program to rave reviews. The program offers everyone the chance to hear from top PKD experts on topics important to you from the comfort of your own home. Two webinars have already been presented and can be viewed anytime by visiting [www.pkdcure.org](http://www.pkdcure.org). While you are there, take a moment and sign-up for the next live webinar which will take place on March 17th with Dr. Montgomery.

## National Convention on PKD - Empower Yourself

Don't miss the 2009 National Convention on PKD. Join us this summer in Chicago, IL on June 26 - 28, at the Double Tree Hotel Chicago - Oak Brook. Registration is now open for this great educational event. To register please go to [www.pkdcure.org](http://www.pkdcure.org) and click on the 2009 National Convention logo.

*“I quickly realized that these strangers all understood and cared about the disease that has harmed my family for generations. That realization led to the joy of making new friends and realizing that my fate is not sealed. Please come and join me at this year's National Convention on PKD, and see that you are also not alone in your battle with PKD.”*

- 2008 National Convention on PKD Attendee

For more information about this great opportunity for PKD patients and families visit [www.pkdcure.org](http://www.pkdcure.org).



## Phoenix Chapter Calendar of Events

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

**March 2009**  
**National Kidney Month**

**March 2nd - 3rd, 2009**  
**Champions on the Hill Event**  
Washington, D.C.

**March 7, 2009**  
**1st Annual Golf Classic**  
**Sponsored by Integrated Medical Services**

**March 28, 2009**  
**Phoenix Chapter Meeting**

**June 26th - 28th, 2009**  
**National Convention 2009**  
Chicago, IL  
**October 11, 2009**  
**Walk for PKD**  
**Check us out online for specific dates**

**Winter 2009**  
**Holiday Bookwraps**



## The Walk for PKD...Much to be Thankful For

Between September 13th and November 9th, fifty-nine different Walk for PKD events took place in 32 different states. Nationally, the Walk for PKD put nearly \$3 million into the pipeline for critical research funding and for patient education and support.

Thanks to our walk coordinator Dean Benigno and his volunteer team, the Phoenix Walk for PKD raised over \$60,000. In a down economy, this was amazing! Dean also had to have a kidney transplant last year – yet he never skipped a beat planning and running the 2008 Walk for PKD!

The positive effects of the Walk for PKD go well beyond walk day. The funds raised through the walk help newly diagnosed patients find our website and lessen their fears through its information resources and education. Funds also help us lobby on Capitol Hill for issues important to the PKD population, while supporting clinical trials that may soon lead to a viable treatment.

Because those of us with PKD need a voice, we walk. A cure for polycystic kidney disease is our finish line, so until there is a treatment and ultimately a cure, we walk.

## 4th Annual Walk for PKD

Mark your calendars for our 4th annual PKD Walk on Sunday, October 11th at DC Ranch Marketplace, in North Scottsdale. We need your help to be successful. We are currently accepting Corporate Sponsorships. For more information on how YOU can be an integral part of our fundraising experience, email Dean Benigno, Walk Coordinator, at [phoenixwalk@pkdcure.org](mailto:phoenixwalk@pkdcure.org).

## 1st Annual Golf Classic

Mark your calendars! Lisa Sherrill invites you to join other fellow members on Saturday, March 7, 2009 at the Wigwam Golf Resort. This PKD fundraiser is sponsored by Integrated Medical Services as a benefit for the PKD Foundation, Phoenix Chapter. Shotgun Starts at 8:00 a.m. on the Gold Course. \$120 per golfer (includes golf, cart, drinks & lunch – and opportunity to win raffle prizes). Business sponsorships are also available, starting at \$350.

For more information, please contact: Lisa Sherrill at 623-882-1292 or email [lsherrill@imsaz.org](mailto:lsherrill@imsaz.org) or Lauren Miller at 602-824-4116 or [lmiller@imsaz.org](mailto:lmiller@imsaz.org).

## IGIVE.COM

Now here's a cool way to raise money for PKD every time your shop online! Just search the web through iSearchiGive.com (a new search engine powered by Yahoo!), and you'll be raising a penny or more for PKD every time! Even window shopping helps - you don't even have to buy anything! Check it out. It's free, safe, and easy to register PKD as your cause: [www.iGIVE.com](http://www.iGIVE.com).

## Kidney Kinships - 2 Live 4!

If you'd like to learn more about living organ donor options in kidney transplantation (should you ever need one), check out this new information link: [www.KidneyKinships.org](http://www.KidneyKinships.org). This site was created by our Chapter Coordinator to shed more light on the rarely discussed topic of donor recruitment in living donation. The link also addresses critical questions and provides script templates to help family and friends get involved in your search.