

# PKD PROGRESS

Your Guide to Living with Polycystic Kidney Disease

VOLUME 27 | ISSUE 3 | FALL/WINTER 2011

## Caregivers, Stress, Cardiovascular Q&A's and **MORE!**

PLUS Runners  
and Authors

MAKING A DIFFERENCE

for **PKD**

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



The mission of the PKD Foundation is to promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease and improve the lives of all it affects.

PKD Progress is our magazine for patients, physicians and research scientists. Views expressed in the professional articles are those of the individual contributors and do not reflect the opinion of the PKD Foundation.

## A MESSAGE FROM OUR BOARD OF TRUSTEES CHAIRMAN



As the year comes to a close, the PKD Foundation is busier than ever.



### LEARN

**2 Ask the Experts:**  
Answers to your critical cardiovascular questions

**4 Taking Care of Ourselves:**  
Self-care for the provider



### RESEARCH

**3 Accelerating Treatments to Patients:**  
Your latest research and development report card



### CONNECT

**6 Racing and Fundraising for PKD:**  
Tampa team comes up with creative fundraisers

**8 A Patient's Perspective:**  
New book shares PKD experiences to help others



### ACT

**7 Be a PKD Champion:**  
New steps you can take to advocate for PKD



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We are wrapping up another great year of our signature Walk for PKD events across the country. We are aggressively pursuing collaborations with pharmaceutical companies to identify and test compounds which, will lead to effective treatments. We are constantly improving the resources available to those looking for more information about PKD. We are always working to be sure PKD is at the forefront of research initiatives. In short, we are proud to be completing another year devoted to our mission: "Promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for Polycystic Kidney Disease and improve the lives of all it affects."

As many of you know, Dan Larson has stepped down as President and Chief Executive Officer, an office he has occupied for the past 17 years. We are forever grateful and indebted to Dan for his leadership, stewardship and hard work as the PKD Foundation grew and accomplished so much during his tenure. A new President/CEO will be named shortly, who we know will build upon those many accomplishments to lead us to great things.

Until then, we'll continue working hard to deliver treatments and a cure, as well as education, support and more, to the 12.5 million people, just like you, who look to the PKD Foundation for help and hope.

In this issue of PKD Progress magazine, we examine the stress related to being a caregiver, as well as updates on our Accelerating Treatments to Patients (ATP) program. We will also introduce you to Scott Bragan, a Tampa father of two dedicated to raising money for PKD doing what he does best – running – and share more about opportunities for you to get involved and take action on behalf of PKD patients everywhere.

I hope you enjoy this issue – as well as the holiday season ahead. Best wishes to you and yours!

Warm regards,

Scott Goodman,  
Board of Trustees Chairman

P.S. As you gather with family and friends this holiday season, please remember the PKD Foundation with a tax-deductible charitable donation. We look forward to your continued support – this holiday season and always!



# ASK THE EXPERTS

## Cardiovascular Q & A

Your critical cardiovascular questions answered by Robert Weiss, MD. The PKD Foundation recently teamed up with Dr. Weiss to present patients with a free webinar on cardiovascular issues. View this webinar and all our archived webinars in the PKD Learning Center at [www.pkdcure.org](http://www.pkdcure.org).

**Q** For the heart problems associated with PKD, which medications are the best ones and which medications are less effective?

**A** ACE inhibitors and ARBs (inhibitors of the RAAS system) are likely best for hypertension, based on theoretical considerations and animal studies, but a study (the HALT clinical trial) is ongoing to prove this in humans.

**Q** How often should one be tested for aneurysms?

**A** If there is no family history of intracranial aneurysms, the recommendation is that screening is not necessary unless you are in a public health risk profession (such as airline pilot, bus driver). If you have a positive family history, you should be screened at least once with MRA and again if you have severe head/brain related symptoms (headaches, neurological symptoms like sudden blurry vision).

**Q** What is the difference between an ACE inhibitor and a Renin inhibitor?

**A** They act on the same hormonal pathway, but at different points of the pathway.

**Q** What is the correlation between PKD and left ventricular hypertrophy and how can patients be diagnosed for left ventricular hypertrophy?

**A** There is a higher frequency than in the normal population of LVH. Diagnosis can be suspected on physical exam and EKG, but is confirmed by echocardiography.

**Q** Is hypertension caused by PKD or by the hormones?

**A** It is not completely known, but most likely this is due to elevated levels of the RAAS system components which is due to the genetic defect. However, worsening kidney failure adds to the risk of hypertension independently of genetics.

**Q** What is the most effective medication to help the kidneys and heart problems if someone is trying to or is pregnant?

**A** Methyldopa (aldomet) is the drug of first choice for hypertension in pregnancy, but will not favorably affect the RAAS system, so once the pregnancy is over, RAAS inhibitors should be resumed.



## GO GREEN – GET PKD PROGRESS ONLINE

Now you can save a tree (and a few dollars on printing and postage) by reading PKD Progress online at [pkdcure.org/progressonline](http://pkdcure.org/progressonline). If you decide you'd like to stop receiving the printed version, you can sign up there for an email reminder each time the new issue is available online. We'll then remove you from the mailing list and invest the savings in research. Check it out at [pkdcure.org/progressonline](http://pkdcure.org/progressonline).

# Accelerating Treatments to Patients

## Your Latest Research and Development Report Card

The third quarter of 2011 continued to be a busy one for the PKD Foundation. Check out our progress in all areas of our research and drug development program in our abbreviated 3rd Quarter Research and Development Report Card below. For the complete report card, as well as updates on our activities in the first half of the year, visit the Research section of our website, [www.pkdcure.org](http://www.pkdcure.org).

### Drug Development/Repurposing

The Drug Repurposing Initiative is at the heart of the Accelerating Treatments to Patients (ATP) program recently started at the PKD Foundation. We define drug repurposing as the process of developing new uses for existing drugs or candidate compounds. The PKD Foundation strategy is to assist biotech/pharmaceutical or other research organizations in evaluating whether their drug candidates have potential as therapeutic agents for PKD. The validation of the cystic animal models is complete, and evaluation of the first two compounds is underway.

### Core Grants

The PKD Foundation is continuing to fund two core grants in 2011:

**1 ADPKD Mutation Database (PKDB), Dr. Peter Harris, Mayo Clinic:** The PKDB has been established to facilitate the characterization of ADPKD gene variants in PKD1 and PKD2, the two genes known to have mutations causative of ADPKD. It is a repository for all variants in these genes, whether likely disease-causing or not. This database displays the most comprehensive listing of all published PKD1 and PKD2 mutations and includes the silent polymorphisms described to date. This information is available to PKD researchers at no cost because of the support of the PKD Foundation.

**2 Electron Microscopy Core Facility for PKD Researchers, Dr. Vince Gattone, Indiana University School of Medicine:** The Electron Microscopy Core

for PKD Research utilizes the Electron Microscopy Center of Indiana University School of Medicine, under the direction of an experienced electron microscopist and PKD researcher, Dr. Vincent Gattone. This core is dedicated to facilitate research on polycystic kidney disease and other hepatorenal fibrocystic diseases and is well equipped to handle most electron microscopy needs. Services are provided at a significant discount because the costs are underwritten by the PKD Foundation.

### Scientific Meeting Support

The PKD Foundation was a major sponsor of the 2011 FASEB Summer Research Conference on Renal Cystic Disease held June 26- July 1. Drs. Peter Harris (Mayo Clinic), Jim Calvet (University of Kansas Medical Center) and Dorien Peters (Copenhagen, the Netherlands) co-chaired the conference, which was held in Saxtons River, VT. Attending were 146 scientists from around the world. The keynote speaker was Peter Jackson from Genentech who spoke about the mapping of disease genes and pathways in renal cystic diseases. Dr. Jared Grantham, one of the founders of the PKD Foundation and the spark behind PKD research, started off the research presentations with a talk about "Polycystic kidney disease research in perspective: From the kitchen floor, to the bench, to the bedside and back."

### Clinical Trial Update

There are four new studies for PKD patients, including:

- Efficacy Study of Water Drinking on PKD Progression, *Kyorin University, Japan*
- A Study to Investigate the Long-term Safety and Efficacy of Tolvaptan in Patients with ADPKD: Extension of a previous clinical trial, *Otsuka, Japan*
- Core A: The Hepato/Renal Fibrocystic Diseases Translational Resource: Creation of a clinical database of information from patients with hepato/renal cystic diseases to expand knowledge in this area and to use for research studies, *University of Alabama at Birmingham*
- Somatostatin Analogues as a Volume Reducing Treatment of Polycystic Livers: A new study evaluating Lanreotide to treat cysts in both liver and kidney, *Radboud University Hospital, the Netherlands*



# TAKING CARE of Ourselves:

## Self-care for the Provider By Howard R. Winokuer PhD

Isolation, frustration, irritability, boredom, depression, anxiety and outbursts of anger are all signs of stress associated with caring for someone with a long-term or chronic illness, says Dr. Charles Figley, one of the country's leading experts in stress. Often times, these signs of stress can be debilitating to the caregiver and preclude our ability to care for our loved ones as we would like. For those of you caring for someone with PKD, you know exactly what I mean.

As a caregiver, you may have experienced extremely high levels of stress, with emotional and physical symptoms, including sleep disturbance, loss of energy and feeling tired, reduced resistance to infection, problems concentrating, headaches, backaches, muscle aches and gastrointestinal complaints. All of these symptoms are normal but avoidable.

Caring for oneself while caring for others is critical; not only to help us take care of our loved ones, but also to help us be able to take care of ourselves. **The following tips, suggested by Dr. Alan Wolfelt, are not meant to be all inclusive. Pick the ones that you believe will help you in your efforts to stay physically and emotionally healthy.**



**Recognize that when you are caring for a loved one, there is a high risk for burnout.** While helping your family member has its rewards, it also has its dangers. Keeping yourself aware that you are "at risk" for burnout will help keep you from denying the existence of stress related signs and symptoms.



**Remind yourself** that mistakes are an integral part of learning and growth and are not reflections of your self-worth.



**Practice setting limits** and alleviating stresses you can do something about.



**Learn effective time-management skills.** Set practical goals for how you spend your time. Don't allow time to become an enemy.



**Work to cultivate a personal support system.** A close personal friend can be a real lifesaver when it comes to managing stress and preventing burnout. If you have already reached the crisis state of burnout, realize you may well need the help of others. Many caregivers have trouble asking for help. If this is the case for you, practice giving yourself permission to seek outside support.



**Develop healthy eating, sleeping and exercise patterns.** We are often aware of the importance of these areas for others; however, we sometimes neglect them ourselves. A well-balanced diet, adequate sleep and regular exercise allows for our own physical, mental and emotional well-being.



**Create periods of rest and renewal.** The quickest way to burnout is spreading yourself too thin. Learn to respect your mind and body's need for periods of rest after a long day.



**Be compassionate with yourself about not being perfect.** After all, none of us are!



**Strive to identify the unique ways in which your body informs you that you are stressed.** Do you get tightness in the shoulders, backaches, headaches? Becoming conscious of how your body communicates stress signals to you allows for awareness of stressful situations before they overwhelm you. A constant state of physical tension often results in deterioration which results in physical breakdown.

In conclusion, it is helpful to remember that as we struggle with the stress associated with caring for a loved one with PKD, it is important for each of us to remember that supporting someone who is unable to care for him/her self is not just a responsibility; it is a gift and a privilege.

Howard R. Winokuer, PhD, runs the Winokuer Center for Counseling and Healing in Charlotte, North Carolina. His webinar on emotional issues for PKD patients can be found in the PKD Learning Center at [www.pkdcure.org](http://www.pkdcure.org). Dr. Winokuer can be reached at 704-333-5598, [hwinokuer@carolina.rr.com](mailto:hwinokuer@carolina.rr.com) or [www.thewinokuercenter.com](http://www.thewinokuercenter.com).

## Want more tips and tools for living a healthier, less-stressed life?

Check us out online! Not only can you access archived issues of PKD Progress, you can also browse exciting, in-depth articles and interactive tools to help you live your best life with PKD.



### See what's online this month:

- More Caregiver Resources
- PKD Health Notes Blog, your guide to nutrition and well-being
- Insurance Primer
- GFR Calculator
- Walk for PKD Photos
- And so much more!

Visit [www.pkdcure.org/progressonline](http://www.pkdcure.org/progressonline) today!

# RACING – AND FUNDRAISING – His Way to the Finish Line for PKD

When Scott Bragan makes a promise, he intends to keep it.

So when the Tampa father of two told his wife he'd give her a kidney, he meant it and very soon will begin testing to become a donor.

And when he vowed to raise money for PKD education, advocacy and research, he jumped right in with both feet. His first fundraising event for the PKD Foundation was on the inaugural 2008 Run for PKD team in the Bank of America Chicago Marathon. Then after much excitement and momentum for PKD, he created Team Tampa PKD and led a nine-member team in the 2009 race, raising over \$25,000 during some of the toughest economic conditions we have seen.

Now Scott has planned two more races in 2011 (Disney World Half-Marathon in January and now Bank of America Chicago Marathon in October) and leading 22 runners in a sprint to raise \$50,000 for the PKD Foundation. "As our lives have taken a turn in a very different direction, it has become a personal fight, almost like a ministry or a calling for me, and this is now much bigger than just one family," the 43-year-old Team Tampa PKD Captain says.

Scott's wife Erika and her mother both have PKD. Having just turned 40, Erika's kidneys are operating at about 25 percent, and she's struggling with the very real symptoms of increased blood pressure, nausea and eating issues. Scott and Erika's children, Madison, 10, and Spencer, 7, don't know their mom has PKD, nor do they realize there is a 50 percent chance that they may have the disease as well.

Although Erika has begun the process for getting her name on the National Donor list for a new kidney, the Bragan family has very real concerns, knowing that 90,000 people in the United States are on this list, and on average, it could take up to five years to find a match. That's why Scott has stepped up to donate his own kidney. Testing is going well, and Scott hopes to receive a green light from the doctors in the near future.

Until then, Scott and his team of friends and fellow athletes have been hard at work, training for the 2011 Bank of America Chicago Marathon (sometimes logging in 18-20 miles a day!) and raising thousands of dollars for the Run for PKD team.

So far, they've raised more than \$43,000 through personal solicitations and corporate sponsorships. They've also



From left to right in the picture, Scott Bragan, Karen Grimaldi, Wibke Reese and Brad Minus.

reached out to the community with some exciting and unique fundraisers – known at the PKD Foundation as Independent Fundraising Events, or IFEs.

On August 27, Scott and his team organized the First Annual Poker for PKD Tournament, raising \$1,500 in a few short hours. Other events they held include:

- **PKD - Painting with a Twist**, where participants paid \$45 for a lesson from a professional artist; and at evening's end the artist auctioned off a piece of artwork. Add in wine-tasting with indulgent appetizers, and you have the recipe for success.
- **Party for PKD Research at Mangroves**, a \$10 wristband got you food and drinks at this boutique restaurant and lounge in South Tampa with all the proceeds going to the PKD Foundation.
- **Family Movie Night for PKD**, a donation of \$10 per person for a local movie right out of Clearwater, FL, "A Dolphin Tail" included with a hotdog, popcorn and drink.
- **PKD Dodge Ball Tournament** with teams of five paying \$100 competed at a local trampoline arena.
- **Ongoing: PKD Pub Runs and Garage Sales**, where people can buy raffle tickets and "Finish Strong" wristbands in support of Scott's Team Tampa PKD.

"Our goal is to raise as much awareness and financial support for PKD, the Run for PKD, and the PKD Foundation as possible," says Scott.

# Be a PKD Champion



Ask your Senator to Support the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act

On July 29, Senators Richard Durbin (D-IL) and Thad Cochran (R-MS) introduced the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2011 (S. 1454). This important bipartisan and bicameral legislation will ensure kidney transplant recipients are able to maintain Medicare Part B coverage of immunosuppressive drugs necessary to avoid organ rejection and a return to more costly treatments.

### Background

Medicare covers the full cost of dialysis for a patient's lifetime; however, under current Medicare coverage policy, Medicare will only pay for necessary immunosuppressive drugs for 36 months post-transplantation. Once the 36-month period ends, kidney transplant patients are forced to find other ways to pay for expensive immunosuppressive medications. The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act will ensure kidney transplant recipients are able to maintain Medicare Part B coverage of immunosuppressive drugs by ending the 36-month limit.

### Rationale

According to data from the 2010 Annual Data Report of the U.S. Renal Data System, extending Medicare coverage for immunosuppressive drugs (\$15,000-\$20,000 per year) is far less costly to Medicare than a patient returning to dialysis (\$76,000 per year) or receiving another transplant (\$100,000-\$125,000). As of August 1, 2011, the United Network for Organ Sharing (UNOS) reports that more than 89,000 people are on the kidney transplant wait list. Of this 89,000, approximately 5,000 are PKD patients.

Given the cost data and numbers of those awaiting a transplant, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act makes for good policy and will provide a long term savings to Medicare. Furthermore, kidney transplant patients will no longer have to worry about how to pay for these important medications.

### Take Action Today

The PKD Foundation is a leading voice for the legislation. However in order to pass the bill, we need your stories and urge PKD Champions across the country to contact their Senators asking them to co-sponsor S. 1454. To learn more about the bill and to send an e-mail to your Senators, visit the PKD Advocacy Network at [www.pkdcure.org/advocate](http://www.pkdcure.org/advocate). Now is the time to change this outdated Medicare policy and provide lifelong access to these vital drugs.

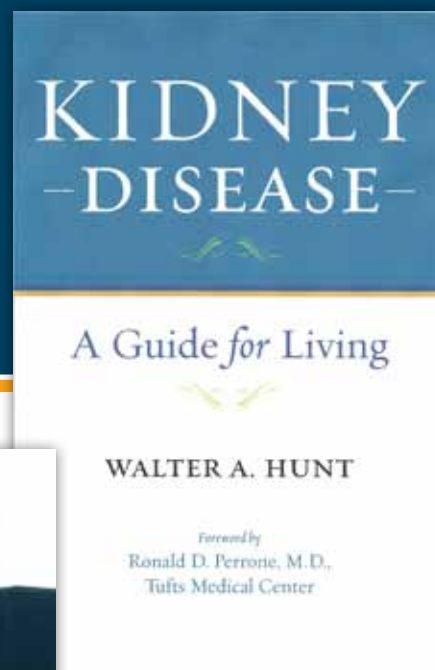
## Save the Date

**WHAT:**  
United on the Hill 2012

**WHEN:**  
June 18 – 19, 2012

**WHERE:**  
Hyatt Regency Washington on Capitol Hill

# New book shares PKD experiences to help others



◀ Walter A. Hunt, PhD

Walter A. Hunt, PhD, knows what it means to live with kidney disease. Dr. Hunt has PKD. In his first book, *Kidney Disease: A Guide for Living*, Dr. Hunt shares his experience and knowledge to help other people with kidney disease understand and cope with its challenges.

*Kidney Disease: A Guide for Living* discusses the latest scientific and medical findings about kidney disease, including what kidneys do; the underlying diseases that cause failure; diagnosis, treatment, and prevention;

medical researcher for thirty years, he examined the biological basis of diseases, never considering that one day he would be dealing with a serious disease of his own. After being diagnosed with PKD, he endured

“I share with readers many of the experiences I had with PKD and ways to cope with the various stages of the disease.”

dietary factors; clinical trials; and the future direction of research on kidney failure.

seven and a half years of dialysis and two dozen stays in the hospital before receiving a transplant.

“I wrote the book to give people suffering from kidney disease a guide that would help them navigate the long and sometimes confusing process from diagnosis to treatment, all from a patient’s point of view,” Dr. Hunt says. “I share with readers many of the experiences I had with PKD and ways to cope with the various stages of the disease.”

Dr. Hunt is currently working on a memoir entitled *Writing My Name in the Snow: How I Adapted to Kidney Failure, Found My Inner Strength and Began Life Anew*.

Dr. Hunt is a member of the PKD Foundation’s Board of Trustees, and is donating 20 percent of book sales to the PKD Foundation. He holds a doctorate in neuropharmacology from West Virginia University. As a

Find more information on *Kidney Disease: A Guide for Living* at [facebook.com](https://www.facebook.com).

## Save the Date



**WHAT:**  
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Hyatt Regency on Capitol Hill

Advocacy is critical to advancing research, leading to the discovery of treatments and a cure for PKD. Join us in 2012 for this exciting and impactful legislative and public policy conference – your chance to advocate for change – and a cure for PKD!

Learn more at [www.pkdcure.org](http://www.pkdcure.org).

## Did you know you can donate your vehicle to raise money for PKD?



The V-DAC (Vehicle Donations to Any Charity) program allows our supporters to donate their vehicles and designate the funds to the PKD Foundation. Any vehicle, anywhere in the United States and Canada, is accepted, and the process is quick and easy!

Learn more in the Donate section of our website, [www.pkdcure.org](http://www.pkdcure.org), or call 877-999-8322.



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## *Health Notes*

A blog by Kelly Walsh,  
Renal Dietician

## Your guide to nutrition and well-being.

PKD Health Notes Blog provides health, nutrition and well-being information to those with Polycystic Kidney Disease (PKD) and other kidney related issues, educating and empowering them to live life to the fullest.



Visit the blog today!

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