

Donations = Grants Funded and People Educated

This year we have many meritorious grants to be funded and thousands of people to educate about PKD! As you think about charitable giving, consider donating to the Iowa Chapter of the PKD Foundation. Eighty cents of every dollar donated supports vital PKD research and patient education.

I would like to contribute under my name.

Name: _____

Address: _____

City/St/Zip: _____

Phone: _____

E-mail: _____

I would like to contribute in [Honor/Memory] of

Name: _____

Please send Acknowledgement to:

Name: _____

Address: _____

City/St/Zip: _____

Phone: _____

E-mail: _____

Please mail donations to:

PKD Foundation

Attn: Iowa Chapter

9221 Ward Parkway, Suite 400

Kansas City, MO 64114

If you would like to contribute via credit card please call 1-800-PKDCURE and mention the Iowa Chapter when you make your contribution.



9221 Ward Parkway, Suite 400
Kansas City, MO 64114

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

Learn more about
the PKD Foundation at
www.pkdcure.org

PKD Foundation

IOWA CHAPTER

WINTER 2010



A Message From Your Coordinator...

2009 Was A Big Success for the Iowa Chapter! Thanks to all who participated in the walk, chapter meetings and the educational seminar. Your support for the chapter and me as coordinator was truly felt. In June I was able to accept the 'Gift of One Another' award for our chapter giving opportunities for sharing our lives with each other in person, at monthly meetings, and by email.

Iowa News This Year:

'Cedar Rapids Man Finds Kidney Through Facebook'

'Le Mars Woman Donates Kidney to Des Moines Stranger'

'Family Honors Newborn Lost to ARPKD'

'Des Moines Man Grateful for Second Chance at Life Given by Deceased Donors Family'

These stories are amazing. Thank you for being willing to share them.

Your Local PKD Foundation Chapter – A Source of Information, Comfort, Friendship and More

John's story

The Burge family has a genetic tendency to polycystic kidney disease, or PKD. Eva Burge, the family matriarch, said the disease was discovered years ago in her late husband, Robert. She donated one of her kidneys to her spouse in 1998. He died in 2008.

Robert was the first person in the family to be diagnosed with PKD, but it is now believed that his mother and an aunt also had it, Eva said. It has affected John and possibly another of Eva's sons, as well as two granddaughters, one of whom is taking part in a research study attempting to find a cure for the disease.

John and Katie Burge attended the national convention of the PKD organization, which was held last summer in Chicago. While there, they went to seminars on how to find a donor match.

But there are a lot of people like John who need a kidney, and those who are willing to donate tend to be bombarded with requests. In September, his children decided to try the Facebook approach. The Davenport native, now a systems engineer who lives in Cedar Rapids, Iowa, found a willing kidney donor just a few minutes after his children put out a request on Facebook. He had searched prior to that by more conventional means that resulted in Etten pairing up with him.

He's now recovering and very grateful to Nick Etten, a friend of his son. Etten saw Matt Burge's Facebook request, messaged his agreement and turned out to be a good match as a live donor for a kidney transplant. Earlier in the year, John and Katie traveled to Des Moines from Cedar Rapids to attend Iowa PKD Chapter meetings. They found a place to share their thoughts and frustrations. When they were unable to attend the November meeting, a patient panel discussion on kidney transplants, the information was emailed to them.

Other members of the Iowa Chapter sent thoughts and prayers to the Burge family and were one of the first phone calls after the new kidney started functioning. John is just one of many, many people who have received encouragement and information by connecting with their local PKD Foundation Chapters. Receiving a PKD diagnosis can be stressful and scary.

If you are feeling alone in your PKD journey or just want to learn more effective ways to cope or live with PKD, consider getting in touch with the Iowa Chapter. Whether you are newly diagnosed or just want to connect with others, the Iowa Chapter is here for you.

CHAPTER INFORMATION

Chapter Coordinator:

Becky Decker

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iowa@pkdcure.org

www.pkdcure.org/iowaChapter

2010 National Convention on PKD



Please join us August 6-8, 2010 in Sunny San Diego for the 2010 National Convention on PKD! The Convention will be held at the Sheraton San Diego Hotel and Marina. Online registration will open on March first. Mark your calendars now for this unique educational and social opportunity!

The PKD Foundation Receives Highest Ratings

Charity Navigator, America's largest evaluator of non-profit organizations, recently gave the PKD Foundation its 4 Star (highest) rating for efficiency. They wrote... **"Only 12% of the charities we rate have received at least 3 consecutive 4-star evaluations, indicating that the PKD Foundation consistently executes its mission in a fiscally-responsible way, and outperforms most other charities in America. This "exceptional" designation from Charity Navigator differentiates the PKD Foundation from its peers and demonstrates to the public it is worthy of their trust."**



The Walk for PKD...So Much To Celebrate!

Thank you to the 11,000+ participants who boldly stood up, stepped out and Walked for PKD this year in one of the 54 events that took place in 29 states. By sharing your stories and reaching out to friends, family, neighbors, co-workers and businesses, you have strengthened the PKD army in the fight for a treatment and a cure! Nationally we have raised over \$2.4 million – funds that will help fuel cutting-edge research (4 therapies in clinical trials and counting), extraordinary patient education (webinars you can engage in from the comfort of your home), life-changing advocacy efforts (lobbying the government to support the Immunosuppressive Drug Coverage for Kidney Transplant Patients) and more! Your passion is making progress possible... and this is why we walk.

A word from your local Walk for PKD coordinator...

I'm thrilled to report that the Des Moines Walk for PKD had 206 participants come out to Walker-Johnston Park on September 19, 2009 and helped raise over \$21,800. A simple idea wrapped around our Vision for a Cure, asking 20 people for \$20, allowed walkers to scale new heights! I would like to give a special thanks to our top, individual fundraisers Cathy Young, Kelly Delveau, John Burge, Brian Coppinger, Melinda Larsen and teams A Cure for Cooper, Team Super'stutz'man, Anyway, Katie's Kidney Krew, Andy's Allies for their tremendous dedication to make a difference. I also want to thank top sponsors, Wellmark Blue Cross and Blue Shield of Iowa and Iowa Kidney Physicians P.C., whose generous support helped underwrite our event expenses to allow more of the funds raised to directly support the PKD Foundation mission. Finally, I want to thank each of the volunteers who dedicated their time & talent on Walk Day and throughout the year to help make the Des Moines Walk for PKD such a success – you are truly appreciated!

2010 Des Moines Walk for PKD – watch for improved Penny Kid's Dash, offsite parking with shuttle bus, traveling top team trophy and loads of fun and fundraising!

-Becky Decker – Walk Coordinator, desmoineswalk@pkdcure.org
www.pkdcure.org/desmoineswalk

Iowa Chapter Calendar of Events

For additional information on our events and upcoming chapter meetings, please visit our website at www.pkdcure.org/iowaChapter.

February 14, 2010

Chapter Meeting

February 28, 2010

Iowa Energy Basketball Game Fundraiser

March 27, 2010

Tentative Educational Seminar

Please check our webpage for updates.

April 11, 2010

Chapter Meeting

May 9, 2010

Chapter Meeting/Family Picnic

June 13, 2010

Chapter Meeting

July 11, 2010

Chapter Support Meeting

August 6-8, 2010

National Convention on PKD
San Diego, CA

August 8, 2010

Chapter Meeting

September 2010

Walk for PKD

October 10, 2010

Chapter Meeting

November 14, 2010

Chapter Meeting

December 12, 2010

Chapter Meeting

All of our Chapter meetings are held at the Johnston Public Library - East Meeting Room located at 6700 Merle Hay Road in Johnston, IA 50131 from 2:00 pm to 4:00 pm. For more details on our chapter meetings and topics, please visit our webpage at www.pkdcure.org/iowaChapter.

National Kidney Month

Your seldom-appreciated kidneys will get their time in the spotlight during National Kidney Month this March. The awareness campaign seeks to communicate the overall importance of keeping these vital organs healthy and functioning.

Increased attention on kidneys will offer many opportunities to get involved with your local PKD chapter program or attend various educational seminars. If you're interested in creating a local event to raise awareness or support research for the disease, the PKD Foundation encourages you to take advantage this special month. Some PKD patients, along with their families and friends, have organized charitable golf tournaments, fashion shows, barbeques and even wine tastings in the name of PKD support and awareness.

Other organizations, such as the National Kidney Foundation and the National Kidney Disease Education Program, will be promoting the importance of prevention and early detection of kidney disease, the ninth leading cause of death in the United States.

Stay Informed Through Email and our Website!

With the rising costs of printing and postage, the Iowa Chapter now does most of its communication through email and the Chapter website: www.pkdcure.org/iowaChapter.

To be sure you don't miss out on the latest information, email iowaChapter@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.