Figuratively and literally, 2008 was a high water mark year for Kidneeds. Many of you in the Iowa City and Cedar Rapids area spent long days last summer helping to sandbag back the Iowa City River only to see it crest the sandbag barriers and destroy portions of the University and surrounding neighborhoods. The Greater Cedar Rapids Community Foundation, Kidneeds’ parent foundation, lost its office and had to relocate for four months while clean up and renovations occurred.

Steve McGuire, who planned to bike 2,711 miles from Canada to Mexico for Kidneeds, lost his home and workplace as the Iowa River flooded the city just days before he was set to leave. Undaunted, he is going to ride for Kidneeds this summer in the world’s most challenging bike race.

Due to the fundraising efforts of many DDD families and friends, we have been able to continue to fast-track our research. In February 2008, Fabrizio Spoleti who has a son with DDD, arranged to have Richard present information on DDD to clinicians and researchers at the Mario Negri Institute in Bergamo, Italy. There we shared our research and entered into new collaborations.

With support from the Tully family’s Milagros Research Foundation, the NIDDK, the NIH Office of Rare Diseases and the Wellcome Trust, we held Kidneeds’ Third DDD Collaborative Meeting in Hinxton, England, in August, 2008. It was recognized as a Wellcome Trust Conference of Excellence.

At the conference, scientists decided that we have a great enough understanding of the disease process that we can begin creating and testing therapies. Ironically but fittingly one of the important and exciting discoveries has been that DDD is caused by uncontrolled activity in the “fluid phase”.

Our thanks to everyone who has made it possible to get to this point in our journey either through their research, generosity of time, scientific contributions or financial support.

While Kidneeds researchers continue to learn more about the disease mechanisms, we are beginning to test therapies specific to DDD in a variety of ways and to participate in clinical trials to tests new drugs for other complement-related diseases that may also benefit persons with DDD. It is truly a high water mark year.

With thanks — Lynne and Richard

In August 2008, 32 scientists met for the Third International Focus Group Meeting on Dense Deposit Disease at the Sanger Center in Hinxton, England. Research presentations were focused on ways to treat DDD, highlighting new findings, raising significant questions that needed to be addressed, and defining the steps required to make new therapies and bring them to clinical fruition.

Scientists came from nine countries to participate in this conference, donating their time and expertise to push this goal forward. We feel privileged to have their guidance and are grateful beyond words to have the support of this amazing group of scientists.
Advances in Research Knowledge 2008-09

1. Several Kidneeds’ scientists are investigating a number of different drugs that can potentially halt or slow down uncontrolled complement activity.

2. Last year, Kidneeds’ scientists identified the component proteins in the dense deposits as breakdown products (i.e. ‘garbage’) from the complement system. The ‘garbage’ gets trapped in the filtering units of the kidneys because it overwhelms the normal collection systems in the body. This novel finding and the procedure that lead to its discovery received prominent editorial comments.

3. A recent editorial in Nature-Reviews quoted Kidneeds’ scientists who have proposed the use of a centralized repository of treatment and outcomes data to guide the management of patients with DDD. Kidneeds’ scientists have also suggested that the number of participants required to evaluate novel interventions for DDD could be aided by a Bayesian approach, whereby assumptions are made in advance about the likely effect of treatment. Such flexible thinking is likely to benefit patients more than a rigid adherence to the current hierarchy of clinical evidence. The editorial concludes by saying that perhaps it is time to question, rather than simply reiterate, the dogma that randomized clinical trials are absolutely necessary.

4. The role of C3 Nephritic Factor (C3NeF) in DDD is being studied in Wales. Most patients with DDD have this autoantibody. What does it do? These scientists will find out.

5. Research labs at the University of Iowa now tests any patient with DDD anywhere in the world for genetic variations associated with DDD and for C3NeF and auto-antibodies to another protein called Factor H. They are also looking at the complement ‘garbage’ in the circulation as a marker of disease activity. Scientists at the University of Pennsylvania are helping in this effort. All of these tests are free.

6. Nephro-pathologists in Arkansas are continuing to study renal biopsies from persons with DDD to provide links between what is seen on biopsy samples and disease progression.

Face-to-Face

For the past 3 years, we have held a family conference in Iowa City for DDD families. This forum has provided families with a chance to meet each other. Children and adults on dialysis can share their experiences and everyone can learn about the latest in research finding and how much progress is being made.

We are planning another family meeting this year. It will be held in early August. If you are interested in attending, please contact Lynne. We will also be in England for a meeting in July. If you live in the UK and interested in organizing a family meeting there, please let Lynne know. If you cannot attend and you are in the Iowa City area, you are always welcome to stop by for a private mini-meeting.

FACEBOOK

In an attempt to keep up, I have set up a Kidneeds’ Families group on Facebook. It is invitation only, which means that people who are not part of the group can only view the group description but cannot see the wall or the bulletin board. If you are a DDD patient or family member, you can join the group. For instructions, please email me at: Kidneedsmmpgn@yahoo.com

Connect with other families with DDD — join us on Facebook.
Research Awards for 2009

Research grants are reviewed by our Board of Scientific Advisors in December. This year, eight grants were received and five were funded. A total of $250,000 was awarded to scientists for the next 18-month period.

These grants address issues on:

1. C3NeF: Two scientists in Wales will be doing research in collaboration with scientists in the United States to answer this question.
2. Glycosaminoglycans: A scientist in the Netherlands is looking at the role of glycosaminoglycans in DDD. Glycosaminoglycans (GAGs) are an important component of the glomerulus and heparin sulfate GAGs are lost in DDD and other glomerular diseases.
3. Factor H-Related Genes: In addition to Factor H, which can play an important role in the cause of DDD in some patients, there is a family of genes related to Factor H. Their role in DDD will be investigated by a scientist in Canada.
4. A DDD Mouse: Although scientists have been using a mouse deficient in Factor H as a model of human DDD, there are some differences. A scientist in Chicago is refining the DDD mouse to be a better model of human DDD by making it express the human CR1 protein on red blood cells for proper immune complex processing.

Patient Research Opportunities

Last night, I was reading an article in the Juvenile Diabetes Research Foundation (JDRF) newsletter that was discussing the frustrations of setting up clinical research trials and then not having enough patient participation. This lack of interest can force research trials close due to low enrollment. Advancement in knowledge about a new treatment or facet of the disease is delayed and persons with the disease suffer. This problem is not unique to the well-run JDRF.

DDD is a rare disease and we do not have the luxury of hoping the ‘someone else’ will participate. We have to be that ‘someone else’. Even with a high percentage of participation, it can be difficult to get enough people to enroll in a study and generate statistically significant data (see #3 under ‘Advances in Research Knowledge’). We have been fortunate to have increasing numbers of persons offering to participate.

Please continue to help. Some research studies take time to generate meaningful data. Other research studies can provide information that can be helpful in your care very quickly. For example, scientists may discover that you have an auto-antibody to Factor H that is causing your disease or that you really have Primary Glomerulonephritis with Isolated C3 Deposits, a kidney disease very similar to DDD (see #5 and #6 under ‘Advances in Research Knowledge’).

To find out about research studies that are available for persons with DDD, please contact Lynne Lanning: kidneedsmpgn@yahoo.com

2008-2009 Fundraisers

Carol Personte held her 9th annual Golfing Fundraiser in Webster, NY. The new twist was a crazy golfing outfit award. Carol’s daughter, Gabrielle has DDD.

Karen Williams raised $8,000 at her first walk-a-thon for Kidneeds. Karen’s nephew, Tommy Kane, was recently diagnosed with DDD. She is planning another this fall in Pennsylvania.

Tommy Kane is planning a bat-a-thon with his softball team to help raise funds in Ohio.

Michelle Stumpf held her fifth walk-a-thon for Kidneeds in CT. Even though it poured minutes into the walk, it was still fun and raised over $8,000.

Hope Tully and friends in London held a gala dinner event for Kidneeds that raised over $62,000.

Seiko Mizuta-Spencer, Hope’s friend, organized a fundraiser of highly talented, young musicians for a magical evening in Hampstead, London. The event raised $3,000.

Steve McGuire from Iowa had an EnduroCure for Kidneeds that raised over $40,000 with help from DDD families and friends worldwide. Watch the website for information on his upcoming 2745 mile bike ride for Kidneeds in June.

Peter Tease and his friends in Iowa City held several lemonade stands to raise money for Kidneeds.
Kidneeds is a fund of the Greater Cedar Rapids Community Foundation. Ninety five percent of the funding for Kidneeds comes from individuals, most of whom know only one person with DDD. **One hundred percent of your donation to Kidneeds will be used for research on DDD.** Administrative costs are paid privately. To help us to continue funding DDD research, you can write a tax deductible check to: Kidneeds, GCRCF and send it to: The Greater Cedar Rapids Community Foundation, 200 First St. SW, Cedar Rapids, Iowa 52404. If you prefer to make an on-line donation to Kidneeds, visit the Kidneeds website at http://www.medicine.uiowa.edu/kidneeds/ and click on the box at the top right. Kidneeds can also receive United Way gifts, gifts of stock and other forms of donations.

For more information on making a donation, please speak with Josie Velles, 319-366-2862 at the Greater Cedar Rapids Community Foundation.

Kidneeds
11 Cherry Lane NE
Iowa City, Iowa 52240

TO:

**Things to check**

1. **Dense Deposit Disease Outcomes Database.** This is an outcomes database for physicians who treat DDD patients. Contact Dr. Richard Smith at richard-smith@uiowa.edu or visit https://genome.uiowa.edu/ddd/
2. **Sulodexide.** Drug trial for DDD patients. Contact Dr. Richard Smith at richard-smith@uiowa.edu.
3. **Research opportunities.** Complement studies, genetic analysis and pathology studies. For more information on these studies, contact Dr. Richard Smith at richard-smith@uiowa.edu.
4. **New MPGN database.** Ensure that the information we have on you about DDD is correct and current. Please contact Lynne at kidneedsmpgn@yahoo.com or visit https://mpgn.nursing.uiowa.edu.
5. **Fundraisers.** Plan one for this year. Visit www.medicine.uiowa.edu/kidneeds and contact Lynne. She will post information about your fundraiser on the Kidneeds Website.
6. **Family DDD conference in USA.** Visit Iowa City, Iowa, Saturday, August 1st. For details, please contact Lynne at kidneedsmpgn@yahoo.com.
7. **Family DDD conference in England.** Lynne and Richard will be in England in July. Are you interested in attending a 3-hour family DDD conference on the weekend of July 11-12? Contact Lynne, kidneedsmpgn@yahoo.com.
8. **Get-well pillows.** Available for young DDD patients. Request one at kidneedsmpgn@yahoo.com.