

Searching for a cure



Cystinosis Research Network

# Cystinosis Research Network Newsletter

HOPE through Research, Education, & Family Support

Spring/Summer  
2007

## Cystinosis Research Network Family Conference

July 19 – 21, 2007

The Hotel Contessa, San Antonio, Texas

*“Searching for a Cure.....Deep in the Heart of Texas”*

By Christy Greeley

The Cystinosis Research Network is pleased to announce its Family Conference will be held July 19-21, 2007 at The Hotel Contessa ([www.thehotelcontessa.com](http://www.thehotelcontessa.com)) in San Antonio, Texas. People from all over the world will come together for three days of exciting lectures, workshops, and sharing. Clinicians and researchers will present leading edge information, answer questions, and share their insights. All of this will take place in beautiful San Antonio, Texas at The Hotel Contessa, located on the Riverwalk in the heart of San Antonio.

A new addition to this year's conference will be a poster session which will showcase a mix of science, medicine, industry, advocacy group, and patient experiences to provide an interactive experience for both family and professional attendees. Researchers, clinicians, industry and advocacy representatives, students, patients, and caregivers will be invited to exhibit their latest research findings, treatment breakthroughs, advocacy group updates, and real patient and family experiences. This will be an interactive session where exhibitors will be available to discuss their work or experiences with those attending.

We are pleased to announce that Shad Ireland will be joining us in San Antonio to help kick off this year's conference as our inspirational speaker. Shad is an individual who has accepted, and is successfully living with kidney disease and all of the experiences that go along with this diagnosis. On July 25th, 2004 he became the first dialysis patient to ever compete in and complete an Ironman triathlon. You can learn more about Shad on his websites at [www.shadirelandfoundation.org](http://www.shadirelandfoundation.org) or [www.ironshad.com](http://www.ironshad.com). We look forward to meeting Shad in San Antonio and hearing about his amazing life.

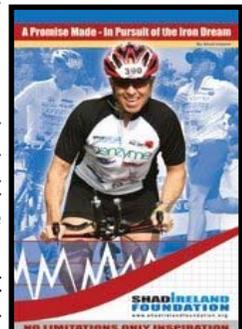
Registration packets were mailed in early April – if you have not received one and wish to, please contact Pam Woodward at [rptswood@csolutions.net](mailto:rptswood@csolutions.net) or (801) 404-6119. You can also access conference information, including registration and scholarship forms, agenda, and poster session requirements on the CRN website at [www.cystinosis.org/conferences.html](http://www.cystinosis.org/conferences.html). We hope you will all join us in San Antonio this summer!

President's Message	2
Financial Update	4
Research Update	4-5
Research Studies	6, 10-11
Cystinosis Mexico	7-8
Call for Action	9
Cystinosis Mexico	7
Success Stories	9-10
Fundraising Calendar	14
Fundraiser Profiles	15-18
In Memoriam	18
Scholarships	19-20
Membership	21-22
Donate	23
Gifts and Donations	24

### CRN Vision and Mission

**Vision.** *The Cystinosis Research Network's vision is the discovery of improved treatments and ultimately a cure for cystinosis.*

**Mission.** *The Cystinosis Research Network is a volunteer, non-profit organization dedicated to supporting and advocating research, providing family assistance and educating the public and medical communities about cystinosis.*



**BOARD OF DIRECTORS****President**

José T. Morales

**Executive Director /****Vice President Research**

Christy Greeley

**Vice President Development**

John Shepperd

**Vice President****Education and Awareness**

Marybeth Krummenacker

**Vice President Family Support**

Pam Woodward

**Treasurer**

Brittney LeBeau

**Secretary**

Frankie McGinnis

**Newsletter and Website**

Paula Shal

**DIRECTORS**

Cheri Friend

Sandy Glaize

Karen Gledhill

Dave Greeley

Kathleen Harrison

Carol Hughes

Dan Julian

Mack Maxwell

Paula Shal

Lynn Thomas

**SCIENTIFIC REVIEW BOARD****CHAIRPERSON**

William A. Gahl, M.D., Ph.D.

**MEMBERSHIP**

Adam J. Jonas, M.D.

Frederick Kaskel, M.D., Ph.D.

Craig B. Langman, M.D.

William Rizzo, M.D.

Jerry A. Schneider, M.D.

Joseph D. Schulman, M.D.

Jess G. Thoene, M.D.

**MEDICAL ADVISORY  
COMMITTEE**

Donald Cairns, Ph.D.

Ranjan Dohil, M.D.

Ewa Elenberg, M.D.

Julie Ingelfinger, M.D.

Robert Kleta, M.D., Ph.D.

Minnie Sarwal, M.D., Ph.D.

Susan E. Thomas Schendel, M.D.

Doris A. Trauner, M.D.

**PROFESSIONAL ADVISORY  
COMMITTEE**

Maya Doyle, LCSW-R

David Glaize, Ed.D.

Charles E. Morrill, M.D.

Nick Smith, LCMHC

## Message from the President José T. Morales

If you haven't heard, the 2007 Cystinosis Research Network Family Conference will be held in San Antonio, Texas – **“Searching for a Cure.....Deep in the Heart of Texas!”** We hope you will plan to attend as the agenda will be filled with important information for our entire community.

We have endeavored to provide opportunities for you to participate in stage specific, relevant sessions to ensure you have a heightened awareness of what is taking place and for you to be able ask questions pertinent to the challenges you are facing today and in the future. Please visit our website to get additional details around the entire Family Conference experience planned for you!!!!

CRN has extended invitations to non-profit cystinosis organizations worldwide to attend this year's conference: Cystinosis Foundation - USA, Mexican Cystinosis Association, Cystinosis Foundation - UK, Cystinosis Foundation - Australia, Cystinosis Foundation - Ireland, Cystinosis Foundation - Germany, Cystinosis Foundation - Venezuela, and the Cystinosis Research Foundation. We hope they will be all able to join us in San Antonio in order to foster closer collaboration between all of the organizations focused on the issues surrounding cystinosis and to further our mutual objectives and missions.

The following are a few highlights of this year's activities:

**Governance** – A Nominating Task Force, under the leadership of Dave Greeley has been formed and is in the process of identifying qualified candidates for Board and Executive Committee officers completing their terms. We will announce the newly elected officials during the Family Conference in Texas. Please contact Dave if you an interest in a specific position.

**Research** – We are currently supporting six research grants focused on Cystinosis totaling over half a million dollars. A Call for Proposals is planned for the month of April and will mark the 5th year of consecutive calls.

In the event you missed it, a major effort is about to commence for creating a kidney tissue repository focused on Cystinosis. This work has been in the planning stage for multiple years and Dr. Jess Thoene was finally able to secure the necessary authorization. This is a very exciting development as it will enable our research community to rapidly access cystinotic tissue to conduct their work.

**Development** – We continue to make progress in this critical area. John Shepperd has made substantial progress along multiple fronts and we currently are projecting to raise over \$300,000. As always, we have more needs than funds so please consider sponsoring a fund raiser on behalf of our community. Please contact John to explore how you can assist.

continued from page 2

**Education and Awareness** – This is one of our most critical activities and I cannot over emphasize the need for greater involvement from our community. In 2007 we committed to attend two professional conferences: University of Miami Pediatric Seminar, by invitation only, (Miami, Florida; March 3 – 6, 2007) and the American Society of Pediatric Surgeons (Toronto, Canada; May 5 – 7, 2007). We hope to participate at the American Society of Nephrology (San Francisco, California; November 1 – 4, 2007) but will not commit until our financials are secure coming out of this year's Family Conference. Please contact Marybeth Krummenacker if you are interested in attending and representing our community.

**National Organization of Rare Diseases (NORD) Award** – Dr. Bill Gahl was recently selected to receive the NORD's Public Health Leadership Award. The award recognizes Dr. Gahl's commitment to improve the diagnosis and treatment of rare metabolic diseases and stewardship of the National Institutes of Health Office of Rare Diseases (NIH ORD) Intramural Program. Christy Greeley, Marybeth Krummenacker and I will represent the Cystinosis Research Network at the black-tie affair in Washington, D.C.

What is it they say? "Time flies when you are having fun." Time has definitely passed quickly these last five years. This coming summer will mark the end of my tenure as the CRN President and as I reflect, I cannot help but feel a sense of pride and accomplishment. We have come a long way in a relatively short period of time and each of you assisted in various capacities. It has been an honor to have collaborated with a group of dedicated parents and an extended circle of friends.....I am always amazed at how much we are prepared to give to sponsor research and improve the quality of life for our children. A heartfelt "gracias" to all of you for your relentless support and faith.

Warmest regards,

José Morales  
President,  
Cystinosis Research Network



*CRN Board Members Carol Hughes, Pam Woodward, Frankie McGinnis, Marybeth Krummenacker, and Karen Gledhill represented CRN at the American Society of Nephrology Conference in San Diego in November, 2006.*

## CRN Financial Update

**By Brittney LeBeau, Treasurer**

This is my first report to all of you as the Cystinosis Research Network Treasurer. I have been the Treasurer now for 6 months, and I have to admit it has been everything I thought it would be and more! I am very excited about the opportunity to serve our broader community and promise to give it my all!

The bottom line is that the organization's financials are strong. We have a solid foundation from which to work from, and we are forecasting a \$300,000 fundraising target for 2007. As of this first quarter we have 20% of this target already realized!

Our budget for 2007 is official, and I am proud to report a balanced budget has been achieved without compromising any of our programs. The following is a summary of our 2007 budget:

### **CREDITS - \$312,000**

#### **DEBITS – \$300,000**

- **Executive Director** - \$7,400
- **Secretary** - \$200
- **Treasurer** - \$2,900
- **Committees**
  - Development - \$5,400
  - Education and Awareness - \$23,800
  - Family Support - \$2,900
  - Research - \$192,700
- **2007 Family Conference** - \$60,000
- **Contingency Funds** - \$16,700

In addition to the recently completed budgeting process, I have also embarked on redesigning some of our financial protocols. This activity is with the intent of increasing the visibility to cost management. My expectation is we will be in a position to do more with less once we have timely reports and improved accuracy.

I want to thank everyone who has helped me in transitioning to my new position and for the patience you have extended to me as I continue to learn my responsibilities.

## Call for Research Proposals

**By Christy Greeley, Vice President, Research**

The Cystinosis Research Network is pleased to announce its 2007 Call for Research Proposals. Proposals may be submitted to CRN for review and consideration. CRN utilizes a Scientific Review Board comprised of leading experts on the disease of cystinosis which reviews grant proposals and submits funding recommendations to the CRN Executive Committee. More specifically, the SRB provides independent, objective review and recommendations regarding each research proposal utilizing grant review guidelines established by the CRN Executive Committee and in accordance with the mission of the organization.

Priority is given to interventional research, both clinical and basic, that will lead to improved treatments for cystinosis. New investigators are particularly encouraged to apply. The Chairperson of the Scientific Review Board summarizes its recommendations and presents them to the CRN Executive Committee, which then votes on each proposed project.

Proposals must be submitted by June 15, 2007. Qualified proposals will be reviewed during the annual Scientific Review Board meeting in July. The CRN Grant Proposal Guidelines may be accessed on the CRN website at [www.cystinosis.org](http://www.cystinosis.org).

# Cystinosis Research Update

By Christy Greeley, Vice President, Research

## Current Research Commitments

Following are the six current projects funded by CRN totalling over half a million dollars in research grants:

### **“Early Intervention Trial for Visual Processing Deficit in Cystinosis”**

Doris Trauner, M.D., University of California San Diego, La Jolla, CA

Grant Timeline: August 2003 – ongoing, Award amount: \$112,724

### **“Development and *in vivo* testing of novel therapies for cystinosis”**

Corinne Antignac, M.D., Ph.D., Vasiliki Kalatzis, Ph.D., Hôpital Necker-Enfants Malades, Paris, France

Grant Timeline: October 2005 – September 2007, Award Amount: \$50,000

### **“Design and Synthesis of Novel Prodrugs for the Treatment of Cystinosis”**

Donald Cairns, Ph.D., School of Pharmacy, The Robert Gordon University, Aberdeen, Scotland

Grant Timeline: October 2005 – September 2008, Award Amount: \$97,928

### **“Tissue Repository for Cystinosis”**

Jess G. Thoene, M.D., University of Michigan Medical Center, Ann Arbor, MI

Grant Timeline: Fall 2006 – Fall 2007, Award Amount: \$26,206

### **“Study of ATP metabolism in human cystinotic proximal tubular cells and in humans with cystinosis *in vivo*”**

Elena Levtchenko, M.D., Ph.D., University Medical Center Nijmegen, The Netherlands

Grant Timeline: January 2007 – December 2007, Award Amount: \$68,090

### **“Development of a Cysteamine *in situ* gelling system for the topical treatment of corneal crystals in Cystinosis”**

Dr C Tuleu, University of London, School Of Pharmacy, Dr Olufemi Rabi, Guy's & St Thomas' NHS Foundation Hospital, Mr Ken K. Nischal, Mr Rajnish Sekhri, and Dr William Van't Hoff, Great Ormond Street Hospital and Institute of Child Health

Grant Timeline: Fall 2006 – Fall 2009, Award Amount: £103,000 (approximately \$203,500)

The following two updates were due prior to the newsletter going to print:

## Dr. Cairns Research Update

Dr. Cairns has submitted the following update on his research grant entitled, “Design and Synthesis of Novel Prodrugs for the Treatment of Cystinosis”:

*“The prodrug work is progressing well. We have completed all of the 'chemistry phase' of the project and have now synthesised and characterised a library of > 30 prodrugs. Some of the compounds do have a slight 'chemical' smell, but none smells strongly of sulfur. As regards taste, the two drugs which have been evaluated (i.e. tasted by me!) are tasteless. All of the synthesised prodrugs were assessed for their cytotoxicity using MCF-7 and HUVEC cell lines. This study took longer than anticipated due to the insoluble nature of the compounds, and co-solvents such as ethanol and DMSO were required to solubilise the agents. Preliminary results suggest the prodrugs are not any more cytotoxic than the solubility vehicles used. To determine the ability of the prodrugs to deplete intracellular cystine, we have developed a quantitative HPLC assay in-house which allows for UV detection of cystine, cysteamine and other low molecular weight thiols. This assay method will allow us to show that the prodrugs do, in fact, decompose to release cysteamine within cells and to evaluate the ability of the agents to deplete the high levels of cystine found within cystinotic cells.”*

# Cystinosis Research Update

## Dr. Thoene Research Update

*The Tissue Repository study has begun. Following is a letter detailing how kidney biopsy samples may be submitted for the repository. As the letter explains, you may have your doctor contact Dr. Thoene directly if you would like to donate tissue to the registry. If you have any questions, you may contact Christy Greeley at [crn@cystinosis.org](mailto:crn@cystinosis.org).*



### BOARD OF DIRECTORS

#### Officers

##### President

José T. Morales

##### Vice President Development

John Shepperd

##### Vice President Education

Marybeth Krummenacker

##### Vice President Family Support

Pam Woodward

##### Executive Director & Vice President Research

Christy Greeley

##### Secretary

Frankie McGinnis

##### Treasurer

Brittney LeBeau

##### Directors

Sandy Glaize  
Karen Gledhill  
Dave Greeley  
Kathleen Harrison  
Carol Hughes  
Dan Julian  
Mack Maxwell  
Paula Shal  
Elva Smith  
Lynn Thomas

##### Scientific Review Board

##### Chairperson

William A. Gahl, M.D., Ph.D.

##### Membership

Adam J. Jonas, M.D.  
Frederick Kaskel, M.D., Ph.D.  
Craig B. Langman, M.D.  
William Rizzo, M.D.  
Jerry A. Schneider, M.D.  
Joseph D. Schulman, M.D.  
Jess G. Thoene, M.D.

##### Medical Advisory Committee

Donald Cairns, Ph.D.  
Ranjan Dohil, M.D.  
Ewa Elenberg, M.D.  
Julie Ingelfinger, M.D.  
Robert Kleta, MD, PhD  
Minnie Sarwal, M.D.  
Susan E. Thomas Schendel, M.D.  
Doris A. Trauner, M.D.

##### Professional Advisory Committee

David Glaize, Ed.D.  
Charles E. Morrill, M.D.  
Nick Smith, LCMHC  
Maya Doyle, LCSW-R

## Cystinosis Research Network, Inc.

302 Whytegate Court, Lake Forest, IL 60045

Toll Free: (866) 276-3669

Tel: (847) 735-0471 Fax: (847) 235-2773

CRN@cystinosis.org www.cystinosis.org

## ~ HOPE through Research, Education, & Support ~

To patients and parents of children with cystinosis:

A tissue repository for renal tissue from patients with cystinosis is being established, with funding from CRN, at the University of Michigan. The existence of this repository will enable ongoing study of cystinotic tissues, which is currently hindered by lack of available tissue.

If you want to participate, please request that appropriate tissue samples be forwarded by the pathologist who analyzed your or your child's renal tissue, whether obtained at renal biopsy during management of the disease, or at transplantation, and who has custody of the sample, to the repository at the University of Michigan. The samples will be maintained confidentially. The identity of each patient will be unknown to University of Michigan Repository staff, but will be marked with an identifier so that samples can be retrieved if future clinical needs dictate. Acceptable samples include unstained slides, or portions of paraffin blocks, depending on the amount of tissue available. All donations must comply with applicable hospital and State laws and requirements.

If you are interested, please ask your nephrologist or pathologist (if known) to contact Dr Jess Thoene at the University of Michigan, Division of Pediatric Genetics, 734-272-5573 who will cover details of sample coding and clinical summary to preserve confidentiality and ensure appropriate shipping. Please do not contact Dr Thoene directly, as this will violate confidentiality.

Funds are available to cover the costs of shipping of the specimen.

## Update from Cystinosis Mexico AC

### 4<sup>th</sup> Cystinosis Medical Symposium is a Great Success! January 25<sup>th</sup>, 2007, Marquis Reforma Hotel, Mexico City

#### By Victor Gomez

The 4<sup>th</sup> Cystinosis Symposium in Mexico city was a great success! Physicians from all over the city attended to listen to information related to cystinosis. Diagnosis, treatment, transplant, and research were some of the topics of the day. We had some important visitors to our country including Dr. Ewa Elenberg, Dr. Craig Langman and for the first time, Dr. Alexander Mendez from Cystinosis Foundation Venezuela. These doctors were important participants of the agenda of this 4<sup>th</sup> symposium.

The day began with **Leticia Belmont, MD**. She defined cystinosis and discussed its symptoms and treatment. She also talked about current information about patients in Latin America, including Mexico City.



*Dr. Leticia Belmont, Victor Gomez, and Dr. Ewa Elenberg pose with patients with cystinosis who attended the 4th Cystinosis Medical Symposium in Mexico*

**Maria Gonzalez, Ophthalmologist** discussed eye care in patients with cystinosis. As we already know cysteamine eye drops do work on the crystal corneal improvement, but she also said that some eye lubrication can help. She compared those who use cysteamine eye drops and those who don't.

**Paz Angelica Camarena, MD** discussed kidney transplantation in patients with cystinosis and the special care needed after transplant.

**Craig Langman, MD**, our special guest from the U.S., continued talking about what happens after kidney transplantation. His presentation included immunosuppression protocols, rejection, long-term graft viability, kidney function, infections, cysteamine treatment, and some important stages every patient goes through after kidney transplant.

**Ewa Elenberg, MD**, our second special guest from the U.S., gave an enjoyable presentation about stages of cystinosis that were familiar with everyone. Her topics included cystinosis therapy, fanconis syndrome, and doses of medicine. She offered tips on how to flavor the medicine and provided great thoughts between slides about the emotions of families dealing with cystinosis. She also provided some information about global cystinosis resources.

**Alexander Mendez, MD**, our third special guest, came from Venezuela. He officially introduced Cystinosis Foundation Venezuela. He shared with us his two first cases of cystinosis—a boy and a girl who have nephropathic cystinosis and an unfortunate economical situation. He researched cystinosis web pages, made phone calls, and sent e-mails to try to help them. He was given as a donation some cystagon and became interested in helping more patients with cystinosis. He is the current president of Cystinosis Foundation Venezuela. More information about Cystinosis Foundation Venezuela can be found at [www.cystinosismexico.org](http://www.cystinosismexico.org).

*Continued on page 8*

## Update from Cystinosis Mexico AC

*Continued from page 7*

Finally, **Victor Gomez**, President of Mexican Association of Cystinosis presented some history of Cystinosis worldwide organizations and how Cystinosis Mexico started. He mentioned some activities that our Mexican organization has done since its inception five years ago. He explained Cystinosis Mexico Support Project 2007 which includes: support to Latin-America, research project of molecular analysis on Mexican population, awareness of cystinosis in main cities of Mexico, and special medical care to our Mexican patients.

Those were some of the highlights of our 4<sup>th</sup> Cystinosis Medical Symposium. We really appreciate the support of Dr. Langman, who also serves on the CRN Scientific Review Board and Dr. Elenberg, who serves on the CRN Medical Advisory Committee. Their support is very important to us. Thanks also to our main sponsor **Genzyme Lab**.

We want to invite you to our 5<sup>th</sup> Cystinosis Main Family Conference which will be held in Acapulco, Mexico, February 2008.



**Left:** Dr. Craig Langman focused on transplantation as part of his presentation at the 4<sup>th</sup> Cystinosis Medical Symposium in Mexico City



**Right:** Dr. Alexander Mendez introduced Cystinosis Foundation-Venezuela to the families and medical professionals at the 4<sup>th</sup> Cystinosis Medical Symposium in Mexico City

## Pediatric Nephrology Seminar



The 34<sup>th</sup> Pediatric Nephrology Seminar took place in Miami Beach, FL March 3-6, 2007. Representatives from CRN attended the seminar, and for a 3<sup>rd</sup> year, CRN endorsed medical students/young faculty/trainees in the field of pediatric nephrology from around the world. Dr. Gaston Zilleruelo, Program Chairman of the seminar, is joined by several in the medical profession from South America. Dr. Frederick Kaskel, a member of CRN's Medical Advisory Board, presented several topics relating to CKD and Transplantation. Many of the physicians in attendance from around the world currently have cystinosis patients under their care.

## Kidney Care Quality & Education Act

*The Cystinosis Research Network is committed to keeping abreast of legislation that may impact our community. The Kidney Care Quality & Education Act is currently being processed through Congress. We encourage the cystinosis community to take action by contacting your respective congressional representative and requesting their full support of this act.*

### Improve Dialysis with Kidney Care Quality and Education Act

Over 335,000 Americans require dialysis at least 3 times per week to stay alive. Most of these people depend on Medicare to pay for treatments. Although dialysis has improved over the past decade, more can be done for people on dialysis.

Ask your Members of Congress to co-sponsor the Kidney Care Quality and Education Act (HR 1193 / S 691) to empower people affected by chronic kidney disease to make the best treatment choices for their situation and improve care for people on dialysis.

Send a message to the U.S. Congress!

#### **This bill would:**

- Establish an education program for patients before they reach kidney failure to empower them to plan ahead and make the best treatment choices for their situation. Classes would explain dialysis and transplant options, how to manage health conditions that accompany kidney disease, and coping with emotional and financial issues.
- Set up a three-year pilot program to look at how to improve the dialysis patient experience, and set standards and use rewards for providing quality care.
- Examine barriers to home dialysis therapy and ways to remove those barriers.
- Create a national training standard for dialysis technicians to ensure quality care.

**Please act now by asking Congress to support this important legislation.**

## Comparison of the Two Types of Dialysis

### Hemodialysis

- Uses a special type of filter to remove excess waste products and water from the body
- Blood passes through the filter in the dialysis machine and back to the patient. Waste is filtered into a solution in the machine
- Requires a graft to be surgically placed between an artery and vein in the arm or leg
- Takes place in a hemodialysis unit at a clinic or hospital
- Typically needed three times a week
- Typically lasts 2 1/2 to 4 1/2 hours

### Peritoneal Dialysis

- Uses a fluid that is placed into the patient's stomach cavity through a special plastic tube to remove excess waste products and fluid from the body
- The body's own intestinal walls act as a filter when the fluid is pushed into the body
- Requires a plastic tube called a dialysis catheter to be placed in the abdominal wall and through the abdominal cavity
- Requires more involvement from the patient
- Can be done at home
- Must be done every day

# Participants Sought for Cystinosis Research

**The Pediatric Neurology Research Group at the  
University of California, San Diego (UCSD)  
is conducting the following research studies on cystinosis:**

## **Brain and Cognitive Development in Cystinosis**

The UCSD Pediatric Neurology Research Group is conducting a study to examine cognitive and brain development in individuals with cystinosis. Participants will include individuals with cystinosis ages 3-7 years and ages 12-17 years. This study will involve two 2-hour psychometric testing sessions that are scheduled at your convenience. The testing is non-invasive and behaviorally-oriented, and it helps us learn more about the cognitive and behavioral effects of cystinosis. Individuals will be asked to perform such tasks as putting together puzzles, defining words, and identifying or remembering pictures. Your participation in the psychometric testing is entirely voluntary.

As part of the study, Dr. Doris Trauner would like to conduct neurological examinations and Magnetic Resonance Imaging (MRI). Again, participation is voluntary. The neurological examination is a non-invasive exam that helps us learn more about an individual in terms of coordination, reflexes, sensory skills, language, and other neurologic functions. Individuals may be asked to do such tasks as kick a ball, stack blocks, and repeat sounds. MRIs are also considered safe and non-invasive and enable us to learn more about the structure of the brain.

Dr. Trauner hopes to examine any changes in the brain and cognitive development over time by seeing individuals for follow-up testing two years after their initial visit.

If you would like to participate in the Cognitive and Brain Development study or if you would like more information, please contact Jenny Williams at UCSD:

j7williams@ucsd.edu  
858-822-6800

\*\*\*\*\*

## **Executive Functioning in Cystinosis**

The UCSD Pediatric Neurology Research Group is conducting a study to examine executive functioning, which includes behaviors such as problem solving, planning, attention, and impulsivity, in individuals with cystinosis. Participants will include individuals with cystinosis ages 8 years through adulthood. This study will involve two 2-hour psychometric testing sessions. The testing is non-invasive and behaviorally-oriented, and it will help us learn more about executive functioning in cystinosis. Individuals will also be asked to fill out a questionnaire regarding behaviors such as planning and attention. Participation in this research study is completely voluntary.

If you would like to participate in the Executive Functioning study or if you would like more information, please contact Lynne Babchuck at UCSD:

lbabchuck@crl.ucsd.edu  
858-822-6800

~~~~~  
Thank you very much for your time and consideration. We look forward to seeing you! We greatly appreciate the time and effort that families have devoted to increasing our knowledge of the effects of cystinosis.

## Participants Sought for Cystinosis Research

Dear Cystinosis Families,

Dr. Dohil, Dr. Schneider and Dr. Fidler at the University of California, San Diego, are looking for volunteers for their research study. They are currently looking to enroll patients for Summer 2007.

The aim of this research study is to find out if by making changes to the Cystagon tablet it will be possible to take Cystagon every 12 hours instead of every 6 hours. The changes made will stop the tablet dissolving in the stomach. It will instead dissolve in the small intestine. These changes are called enteric coating. The doctors believe that this way more Cystagon will get into the body and its positive effect will last longer. The substance being used for the coating is Eudragit and is produced by Röhm America in New Jersey.

The study started in Fall 2006 and has 3 parts. During the first part the patient will continue their regular Cystagon therapy. The therapy will be monitored closely for 4 weeks by testing white blood cell cystine levels every week. These tests will be done at the patient's regular physicians office.

After these 4 weeks, the patient will be flown to San Diego for some testing. The patient will have to take Cystagon in the morning of 3 different days, first regular Cystagon and then two different doses of coated Cystagon. After taking the tablets, a number of blood samples will be drawn during the next 12 hours. These blood samples will be used to measure the concentration of active component of Cystagon (cysteamine) in the blood as well as measure the white blood cell cystine levels. There will be one rest day between the study days, so the patient will be in the hospital for 5 whole days and 6 nights in total.

The last part of the study will again take place at home. The patient will be given coated Cystagon, which they have to take twice daily for 4 weeks. During this time the success of the therapy will be evaluated by measuring the white blood cell cystine levels every week. These tests will again be done at the patient's regular physicians office. After 4 weeks the patient will resume taking regular Cystagon every 6 hours. The patient will not be able to continue the therapy with coated Cystagon!

For this study, the doctors are looking for about 12 volunteers with cystinosis. The volunteers have to be at least 6 years old, have so far not require a kidney transplant and have to be able to swallow tablets. The coated Cystagon tablets cannot work if they are opened and the contents is dissolved in water and because of this the patient has to always swallow the Cystagon tablets. Patient's participation will also depend on whether their regular physicians can commit to seeing study patients.

Travel expenses for the volunteer and one parent to San Diego will be covered and the volunteers will be compensated for participating in this study. If you are interested in participating and would like more information, please contact Meredith Fidler, PhD, at (619) 543 2049 or [mfidler@ucsd.edu](mailto:mfidler@ucsd.edu).

# Julia Baxter Wins Two Gold Medals!

Julia Baxter won two gold medals at the State Equestrian Competition in Des Moines, Iowa, September 9, 2006. Julia was in the barrel race and the western class. She won gold medals in both classes.

This is Julia's third year in the Special Olympics. Julia's grandfather, Larry Eggers, started the Equestrian team for the Muscatine Special Olympics and is also the coach.

Four days after the Special Olympics in September, Julia competed in the State Unified Golf Tournament. She and her partner won silver medals!

Julia was diagnosed with cystinosis at age one and also has a learning disability that is unrelated to cystinosis.



## Have you visited [www.cystinosis.org](http://www.cystinosis.org) lately?

The Cystinosis Research Network is committed to providing the cystinosis community with information about cystinosis research, resources, fundraising efforts, community achievements, conferences, and more. The cystinosis website ([www.cystinosis.org](http://www.cystinosis.org)) is one channel we use to communicate this information in a timely fashion. Our goal is that the website is current, accurate, and easy to use.

The **home page** on the website outlines recent additions to the site and important events (like the 2007 Family Conference!) The links on the left side of the site provide the cystinosis community with access to loads of information, including:

|                                                                                                                 |                                                                                            |
|-----------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|
| <b>About CRN</b> — CRN By-Laws, Board Members, and more                                                         | <b>Newsletters</b> —Archive of CRN newsletters in .pdf format                              |
| <b>About Cystinosis</b> —Download a brochure for doctors, good description of cystinosis—symptoms and treatment | <b>Research</b> —Latest studies funded by CRN and progress reports                         |
| <b>Community News</b> —Features success stories                                                                 | <b>Resources</b> —Alphabetical listing of valuable medical, financial and family resources |
| <b>Conferences</b> —Special page dedicated to the successful CRN Family Conferences                             | <b>Support</b> —Place to join an online support group                                      |
| <b>Fundraisers</b> —Fundraising calendar with links to details                                                  | <b>Donate</b> —Explains how to donate to CRN online or by mail                             |

## Christian Sproedt's Cystinosis Story

Hi everybody,

I am a 21-year-old German student, and I would like to tell you about how I have successfully managed cystinosis in my life.

I was diagnosed with cystinosis when I was about 2 1/2 years old. I was in a good situation because my children's doctor knew another child with cystinosis.

Directly after diagnosis I started taking Cysteamine and had a typical childhood while attending kindergarten and primary school. My family got in touch with Doctor Harms, the German cystinosis doctor, and the German Cystinosis Foundation was founded. In general I think I was a special child, of course, but I cannot remember special problems with cystinosis.

In secondary school I started taking cysteamine eyedrops, growth hormone, and epoetin for better concentration at school. During this time, until 2001, I played badminton and sang in a choir with whom I did several journeys through Europe. These choir tours were also the first time I learned how to manage my medicine my own, to take a bottle water with me every time, and so on...

In autumn 2000, my kidney function decreased. The results were too bad, and I started with peritoneal dialysis four times a day either at home or in a special private room at school. But I was very lucky. In April 2001 I received a transplant and was transplanted successfully in Muenster, Germany. After recovering in the hospital and at home, I started school again in my old class and was happy that I didn't have to change.

After this big step, I got my Abitur (high school diploma) in 2005 with biology and economics as main subjects. In autumn 2005, I started with a dual study on the staff of DeutschePost (DHL). My study is about business administration and logistics, and I am changing between the theory and the practice every three months. For the practice, I stayed three months in Saudi Arabia at DHL (great time - no medical problems). The next semester, 5th theory semester, I will stay in The Netherlands to study English.

Besides studying, I enjoy free time and went backpacking with a friend in Sweden. During all my trips abroad, I take my medicine with me and have a very good experience with the normal side effects,

Now I am sitting in Lörrach, my university village, next to the border of Switzerland and look forward to enjoying four days of Easter holidays at my family's place next week.

All in all this was more a short life story than a medical story, but if you have any questions don't hesitate to mail the CRN online support group and ask me!

Wish you all the best!

Regards,  
Chris



Christian Sproedt



*Christian Sproedt embraced the Arab culture while working for DHL in Saudi Arabia as part of his school studies.*

## Fundraising Brings us Closer to a Cure

Please consider hosting a fundraiser to help the CRN accomplish its ultimate mission of finding a cure for cystinosis. If you need more information, please contact the CRN at: [CRN@cystinosis.org](mailto:CRN@cystinosis.org) or 1-866-276-3669. Please visit at [www.cystinosis.org/fundraisers.html](http://www.cystinosis.org/fundraisers.html) for the most current fundraising calendar and fundraising results.

### Fundraising Calendar

| Date              | Event                                                                                                 | Location             | In Honor Of            |
|-------------------|-------------------------------------------------------------------------------------------------------|----------------------|------------------------|
| Ongoing           | CRN Note Cards                                                                                        | N/A                  | N/A                    |
| Jan. 9, 2007      | "Shoot for the Cure"                                                                                  | Dalhart, TX          | Mason Reed             |
| Feb. 24, 2007     | "Miracles at Milleridge"                                                                              | Jericho, NY          | Laura Krummenacker     |
| TBD               | Texas Hold Em' fundraiser                                                                             | Athens, IL           | Kenadee Julian         |
| March, 2007       | Jack Greeley's Birthday Fundraising Letter                                                            | N/A                  | Jack Greeley           |
| March, 2007       | Bowling Fundraiser                                                                                    | Bloomfield Hills, MI | Kacy Wyman             |
| March 3, 2007     | Garden Gala for Cystinosis                                                                            | Bloomfield Hills, MI | Kacy Wyman             |
| March 31, 2007    | Ukrop's Monument Ave 10K                                                                              | Richmond, VA         | Alex Weaver            |
| March/April, 2007 | Tahnie Woodward's Soul Scents fundraiser                                                              | N/A                  | Tahnie Woodward        |
| April 15, 2007    | Kirsten Stilke's Partylite fundraiser                                                                 | N/A                  | Mason and Livia Stilke |
| April 29, 2007    | 5K Fun Run/Walk                                                                                       | Bloomfield Hills, MI | Kacy Wyman             |
| May 19, 2007      | Bartending for Charity                                                                                | Byron, IL            | Paula Shal             |
| May, 2007         | Family Fun Day                                                                                        | Greenville, SC       | Laura McGinnis         |
| May, 2007         | 3rd Annual Golf Tournament                                                                            |                      | Neveah Stanford        |
| May, 2007         | Fundraising Letter                                                                                    | N/A                  | Jon Ben & Ava Shepperd |
| August 26, 2007   | 4th Annual Family Fun Day<br><a href="http://www.jacksfamilyfunday.org">www.jacksfamilyfunday.org</a> | Lincolnshire, IL     | Jack Greeley           |
| October, 2007     | 2nd Annual Carnival for a Cure                                                                        | Naperville, IL       | Evan & Alexis LeBeau   |



## “Shoot for the Cure” Raises Over \$1,000

**By Shad Reed**

On January 9, 2007 in Dalhart, Texas, the Dalhart Boys Basketball team hosted the Vega Longhorns. They also hosted a fundraiser to help raise money for the Cystinosis Research Network. The fundraiser was in honor of Mason Reed, nephew of Dalhart head coach Shad Reed and his wife Keva. Mason was diagnosed with Cystinosis at age 3. The fundraiser consisted of a pancake supper. It was a huge success and with numerous donations, the boys raised over \$1,000 dollars for this worthy cause. The support was overwhelming. Two outstanding communities really stepped up. Dalhart Consumers and Jim Turner were the main reason this fundraiser was so successful. They donated all of the supplies and provided their employees to do the cooking. The festivities continued into the boys game when Mason was made an honorary guest of the basketball team. He was introduced in the starting line up before the game and the boys gave him an autographed basketball and wished him luck in the future.



*Mason Reed*

Mason lives in Vega, Texas, which is where Coach Reed attended high school and currently resides, commuting to Dalhart each day, “I thought this would be a great opportunity to get two very special communities involved in a worthy cause to battle this disease. I also wanted to get my boys more involved in real world issues other than basketball. Our program strives on doing what’s right and our “Shoot For The Cure” campaign was a great way to lend a helping hand.” Coach Reed and his basketball team will continue their efforts in helping raise money for Cystinosis research.

Mason is the son of Ryan and Kylene Reed. He also has a younger brother named Jaxon.



*Mason Reed and the Dalhart High School Boy's Basketball team*

## Easy Ways to Raise Money for CRN!

### Search the Internet Using GoodSearch and Raise Money for CRN!



Every time you use GoodSearch.com to search the Internet, a donation is made to the Cystinosis Research Network! GoodSearch.com is powered by Yahoo!, so you get the same great results you get from most search engines. What is unique is that GoodSearch.com has developed a way to direct money to your selected charity with every click!

To get started, go to [www.goodsearch.com](http://www.goodsearch.com). Be sure to select "Cystinosis Research Network" where it says "Who do you GoodSearch for?" Then search like you normally would!

CRN hopes you will give it a try and support Cystinosis Research. The more people who use this site for CRN, the more money is earned. So please tell your friends and family!



### Donate to CRN by Selling on eBay!



CRN has recently signed up with MissionFish, the exclusive charity provider for eBay Giving Works. eBay sellers can now list items through eBay Giving Works and designate a percentage of the sales to go to CRN. The seller picks the percentage, and all money donated is tax deductible. eBay will even refund a percentage of listing and final value fees that is equal to the percentage sellers donate! Items listed with eBay Giving Works are given a special icon, so they stand out. Some sellers report 20-40% higher sale prices for the exact same item using eBay Giving Works. Give it a try, and be sure to tell established eBay sellers about this great opportunity to give to CRN!

### Note Card Fundraiser

The CRN is selling lovely note cards to support cystinosis research. Give a gift that says you care and also supports a worthy cause.

Design options are script initials, floral, "thank you," and more. The inside is blank. The CRN logo and website address is on the back. A set of 8 cards and envelopes is \$10.00 (US), which includes shipping and handling.

Go to [www.cystinosis.org/fundraisers.html](http://www.cystinosis.org/fundraisers.html) to download an order form.

## Miracles at Milleridge

The 3<sup>rd</sup> Miracles at Milleridge Dinner Dance was held on February 24, 2007. Once again, family and friends of the Krummenacker and Finn families came and supported the Cystinosis Research Network in their on-going fundraising efforts. Almost 300 people attended this year's event and from all accounts, they certainly enjoyed the evening.

The evening included a 50/50 raffle, the dinner journal, and of course, the wonderful raffle baskets. This year there were over 50 baskets of donated items that were raffled that night ----everything from dinners to haircuts to New York Knicks tickets! Many attendees went home with some wonderful prizes.

Also on hand was DJ Tom Kenny, who got everyone up and moving the entire evening – he always does a terrific job! A presentation was made to Marybeth Krummenacker by her co-worker, Kurt Ludwig and his brother-in-law, Dave Xavier to thank CRN for their support. The Cystinosis Research Network was the main sponsor of the race car Dave drove at Riverhead Raceway in New York last summer. The CRN logo was proudly displayed on the hood of the car! Kurt presented Marybeth with a plaque that included a photo of the car. As Kurt said that night, "People certainly knew what cystinosis was by the end of each race."

The rest of the evening flew by with dinner, dancing, and raffles. When all was said and done, over \$17,000 was raised for the Cystinosis Research Network. Marybeth has already designated \$5,000 to be earmarked for scholarships for the 2007 Family Conference in San Antonio, Texas.

Special thank yous go out to Nancy & Jerry Finn, Bob and Deb Murphy, Tom & Chris Murphy, Nancy Rooney, Terry Wulforst, Eileen & Al Glueckert (who personally brought 40 people), Will Murphy & Cynthia Alvarez and all those who helped make the evening the huge success that it was. Marybeth hopes to repeat it again in 2009! Photos of the event are coming soon at [www.cystinosis.org](http://www.cystinosis.org) and will be featured in the Fall/Winter newsletter.

## In Memoriam—Jennifer Scharf

Jennifer Scharf, age 20, passed away as the result of an automobile accident in October, 2006. Jennifer did not have cystinosis, but she was an important member of the cystinosis community. Jennifer graduated from Eastside High School in Greenville, South Carolina. Eastside is a proud participant in Wade Hampton week in Greenville. During this week of spirit and fundraising, Eastside High School and Wade Hampton High School compete to see which school can raise the most money for a charity they select. The Cystinosis Research Network has been selected by Eastside High multiple times and hundreds of thousands of dollars have been raised by the amazing kids at Eastside. Jennifer was one of those kids.

Jennifer is survived by her parents, Michelle and Artie Scharf as well as her younger brother, Michael. Jennifer's family knew that finding a cure for cystinosis held a special place in her heart. They have generously requested that memorial donations be made to the Cystinosis Research Network. If you would like to make a donation in memory of Jennifer, please use the donation form on page 22.

## 2007 CRN Scholarship Information

The Cystinosis Research Network has established a scholarship fund to provide supplemental financial assistance to a student diagnosed with Cystinosis who is enrolling in a regionally accredited collegiate or vocational program, or who is currently attending a post – secondary school. The scholarship award, \$1000, is awarded contingent upon the winner's acceptance to an accredited college, university, or vocational program, or documentation of continued enrollment, and will be payable to the educational institution to be applied toward tuition.

An application form is available on the CRN website at [www.cystinosis.org](http://www.cystinosis.org). For more information, please contact: CRN at 1-866-276-3669 or [crn@cystinosis.org](mailto:crn@cystinosis.org).

### APPLICATION PROCEDURE:

Each applicant must submit:

1. Documentation/verification of Cystinosis (e.g. Letter from physician)
2. An official copy of high school transcript
3. Two letters of recommendation from current teachers/faculty members and/or counselors regarding applicant's scholastic aptitude and personal qualifications.
4. An essay of 500 words discussing the applicant's personal and educational goals

**JUDGING CRITERIA:** The essay will be judged on the basis of rationale, grammar, and comprehension. Transcripts and letters of recommendation will be considered in the final decision with Grade Point Average (GPA), courses taken, and class standing used as part of the evaluation. The Cystinosis Research Network Board will establish an independent judging panel to evaluate and rate the applicants. The decisions of the judges are final.

Finalists may be interviewed before selections are made.

**DEADLINE FOR APPLICATION:** Application and all accompanying documents must be received at the Cystinosis Research Network office in a single, flat package postmarked **by August 15, 2007**. FAXES OR E-MAILS WILL NOT BE ACCEPTED.

**PREPARING APPLICATION PACKAGE:** Each application packet must include a complete application (original or photocopied—go to [www.cystinosis.org](http://www.cystinosis.org) to download), required documentation materials and essay, on 8 1/2" X11" white paper. Send all materials in a single, flat package. All application documents become the property of the evaluation committee.

### MAIL APPLICATION PACKETS TO:

Sandy Glaize  
4133 Conway Place Circle  
Orlando, Florida 32812

## 2007 CRN Sibling Scholarship

### Cystinosis Research Network Sierra Woodward Sibling Scholarship

The Cystinosis Research Network has established a scholarship fund to provide supplemental financial assistance to a student who has a sibling diagnosed with Cystinosis who is enrolling in a regionally accredited collegiate or vocational program, or who is currently attending a post – secondary school. The scholarship award, \$1000, is awarded contingent upon the winner's acceptance to an accredited college, university, or vocational program, or documentation of continued enrollment, and will be payable to the educational institution to be applied toward tuition.

An application form is available on the CRN website at [www.cystinosis.org](http://www.cystinosis.org). For more information or to have an application mailed to you, please contact:

Marybeth Krummenacker at [MKRUMM@aol.com](mailto:MKRUMM@aol.com) or 516-931-6785 or

Pam Woodward at [rptswood@csolutions.net](mailto:rptswood@csolutions.net) or 801-404-6119

#### APPLICATION PROCEDURE:

Each applicant must submit:

- An official copy of high school transcript
- Two letters of recommendation from current teachers/faculty members and/or counselors regarding applicant's scholastic aptitude and personal qualifications
- An essay of 300 to 500 words discussing the applicant's personal and educational goals and also the pro and/or cons of how Cystinosis has affected your life

**JUDGING CRITERIA:** The essay will be judged on the basis of rationale, grammar, and comprehension. Transcripts and letters of recommendation will be considered in the final decision with Grade Point Average (GPA), courses taken, and class standing used as part of the evaluation. The Cystinosis Research Network Board will establish an independent judging panel to evaluate and rate the applicants. The decisions of the judges are final.

Finalists may be interviewed before selections are made.

**DEADLINE FOR APPLICATION:** Application and all accompanying documents must be received at the Cystinosis Research Network office in a single, flat package postmarked by **August 15, 2007**. FAXES OR E-MAILS WILL NOT BE ACCEPTED.

**PREPARING APPLICATION PACKAGE:** Each application packet must include a complete application (original or photocopied), required documentation materials and essay, on 8 1/2" X11" white paper. Send all materials in a single, flat package. All application documents become the property of the evaluation committee.

**MAIL APPLICATION PACKETS TO:** Marybeth Krummenacker  
54 Smith St  
Hicksville, NY 11801

**BECOME A MEMBER OF THE CYSTINOSIS RESEARCH NETWORK**  
**Get connected! Stay informed! Together we can find a cure!**

Join The Cystinosis Research Network (CRN) and become part of a global network of caring families, concerned individuals and healthcare professionals working together in the fight against cystinosis. The Cystinosis Research Network's vision is the discovery of improved treatments and ultimately a cure for cystinosis. The CRN is an all-volunteer; non-profit organization dedicated to sponsor and advocate research, provide family support, and educate the public and medical communities about cystinosis. The CRN funds research and programs primarily through donations from the public, grassroots fundraising events and grants.

CRN provides outreach and access to resources. We take great pride in carrying out our motto: "**Searching For A Cure**"...whether you are ...

\* A **Parent** who needs critical resource information, support services or help in sharing the challenges of cystinosis to those who serve your child.

\* An **Adult** with cystinosis interested in information regarding medical and social issues that are specifically geared for adults.

\* A **Relative** or a **Friend** who wants to increase their understanding of Cystinosis and find out how you can help out or become involved.

\* A **Physician, Social Worker, Educator** or other **Professional** who makes a difference in the life of a family affected by cystinosis, and want to have access to critical information to better serve your patient, student or client.

**Joining the Cystinosis Research Network enables you to:**

\* Receive all the latest Cystinosis information through our countless resources, including the CRN Newsletter, our very informative web page [www.cystinosis.org](http://www.cystinosis.org), the ever popular online Cystinosis Support Group and our toll free number (1-866-276-3669).

\* Attend the CRN Family Conference with other Cystinosis Families to exchange knowledge and create friendships. Also, find out the latest discoveries about cystinosis from the medical professionals, following their attendance of CRN's Scientific Symposium, keeping current on scientific advances in Cystinosis research.

\* Let your voice be heard by legislators and policymakers who need to know why Cystinosis (and other rare diseases) are important issues to you.

\* Have access to the Cystinosis Research Network's representatives in the areas that are most relevant at any given time to you or your loved one affected by Cystinosis.

**Join the Cystinosis Research Network today!**

Thank you for your consideration in becoming a member of the Cystinosis Research Network.

Pam Woodward  
VP Family Support, Membership Committee, Chairperson  
Cystinosis Research Network

### Cystinosis Research Network Membership Form:

- Immediate Family:.....\$20.00     Extended Family / Friend:.....\$25.00  
 Professional:.....\$35.00     International: (Including Canada) Base rate (see above categories)  
 plus \$10.00 for postage. Payable in US dollars

Please complete the form & mail with check payable to CRN to: CRN, 302 Whytegate Ct., Lake Forest, IL 60045

Name \_\_\_\_\_

Street \_\_\_\_\_

City & State \_\_\_\_\_ Zip Code \_\_\_\_\_ Country \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_ Email \_\_\_\_\_

Name of Child / Adult / Acquaintance / Patient affected with cystinosis: \_\_\_\_\_

**Please join a Cystinosis Research Network (CRN) Committee and make a difference in the quality of life of children, adults, and families affected by cystinosis. Many opportunities are available.**

I am interested in joining a committee to help CRN. Please check: \_\_\_\_\_ Yes \_\_\_\_\_ No  
 If yes, please check the committee you would like to join or would like more information about:

- Family Support                       Development                       Education / Awareness  
 Research                                 Finance                                 Membership  
 Professional Advisory                 Other:

For more information, please call CRN at 1-866-276-3669, 847-735-0471 or email [crn@cystinosis.org](mailto:crn@cystinosis.org) or visit [www.cystinosis.org](http://www.cystinosis.org). Thank You!

## Join A CRN Support Group

***Looking for a way to communicate with others in the Cystinosis Community on a day-to-day basis?***

The Cystinosis Research Network offers three email support groups for communicating with others in the cystinosis community:

**The CRN Support Group** is a group for parents, affected adults, caregivers, family, and friends. We also welcome researchers and medical professionals who are interested in cystinosis. This is the place to discuss the various aspects of cystinosis, and how it affects our lives, how we cope, vent our frustrations, share our fears, our hopes, and our dreams.

**The CRN Teen Support Group** is for teens with cystinosis and teenage siblings of children and adults with cystinosis. Connect with other teenagers who are dealing with similar issues. The posts include questions, concerns, ideas and supportive sharing.

To join a support group, visit [www.cystinosis.org/support.html](http://www.cystinosis.org/support.html).

**Please Help CRN In Our Mission of Finding A Cure and Improved Treatments, Providing Family Support, and Raising Awareness**

**YES, I want to help children and adults with cystinosis.**

Enclosed is my tax deductible contribution of: \$ \_\_\_\_\_ made payable to the Cystinosis Research Network (CRN) and mail to: 302 Whytegate Ave., Lake Forest, IL 60045

Name \_\_\_\_\_

Street \_\_\_\_\_

City & State \_\_\_\_\_ Zip Code \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_ Email \_\_\_\_\_

In Honor Of \_\_\_\_\_

In Memory Of \_\_\_\_\_

You may send notification of my gift to:  
 \_\_\_\_\_



**United Way Contribution Guidelines**

Identify the Cystinosis Research Network, Inc. as the agency you want to receive your contribution through the United Way Donor Choice Program.



|                            |                                            |
|----------------------------|--------------------------------------------|
| <b>Agency Name</b>         | The Cystinosis Research Network, Inc.      |
| <b>Non-Profit Tax ID #</b> | 04-3323789                                 |
| <b>Address</b>             | 302 Whytegate Ct., Lake Forest, IL 60045   |
| <b>Telephone</b>           | 1-866-276-3669 (toll free), 1-847-735-0471 |
| <b>Fax</b>                 | 847-235-2773                               |
| <b>E-mail Address</b>      | CRN@cystinosis.org                         |
| <b>Web Page</b>            | www.cystinosis.org                         |

- The local United Way organization will contact The Cystinosis Research Network via phone, fax, or e-mail to request we prepare and submit documentation verifying our status as a non-profit organization.
- The Cystinosis Research Network prepares all necessary documentation and submits it to the respective local United Way organization.
- The local United Way organization processes the documentation and sends a check for the aggregate sum designated for the Cystinosis Research Network.
- The Cystinosis Research Network sends thank you/acknowledgement letters to recognize contributing individuals.

- Donation Reminders**
- Don't forget you can make a secure donation online through Network for Good. Visit [www.cystinosis.org](http://www.cystinosis.org) for more information.
  - Don't forget your company's Matching Gift program.
  - Any gift, large or small, is greatly appreciated!

## Gifts and Donations

The Cystinosis Research Network expresses its gratitude for donations, memorial gifts, and "in your honor" gifts. Thanks to all for giving a gift that continues to give. With the financial support of members and friends, the Cystinosis Research Network continues our mission of supporting cystinosis research, cystinosis education programs, and providing family support. We wish to thank the following individuals and groups whose donations were received between November 1, 2006 and February 28, 2007.

### Ambassadors (\$2,500 - \$4,999)

Jose and Velyna Morales through United Way of New York City in honor of Christian Morales  
Dahn Maier through United Way of New York City in honor of Christian Morales  
Ms Sharon Jester Turney in honor of Christian Morales

### Benefactors (\$1,000 - \$2,499)

Ms Sharon Jester Turney in honor of Christian Morales  
Elva Smith in honor of Mitchell Smith  
Cataldo & Kelly, Inc in honor of Kacy Wyman  
Gorton's Gift Matching Program Matching Gift of Larry LeBeau in honor of Evan and Alexis LeBeau

### Sponsors (\$500 - \$999)

Linda Chappell in honor of Mitchell Smith  
Lawrence & Shirley Manning in honor of Megan Morrill  
Tom & Jodi Pauly in honor of Jack Greeley  
Sara Martin in honor of Shea Hammond  
Thomas & Brenda Melang in honor of Tommy & Sarah Melang  
Group Companies in honor of Shea Hammond- Matching Bill Flannery Gift

### Patrons (\$250 - 499)

Charles Davis in honor of Shea Hammond  
Schering-Plough in honor of Alexis & Evan LeBeau-Matching gift of Rudy Stefanski  
Frederick Kaskel  
Ashley & Lee Kazian in honor of Laura McGinnis  
Jill Morrill/Silpada Designs Jewelry fundraiser in honor of Megan Morrill  
Michael Manna/Reit Management & Research LLC  
Fidelity in honor of Shea Hammond-Matching Maria & William Flannery gift

### Supporters (\$50 - \$249)

Evan Moore in memory of Donna Morrill  
Wendy Todd in honor of Kacy Wyman  
Ann Montefusco in honor of Jack Greeley  
Greeley  
Wagner Funeral Homes in honor of Laura Krummenacker  
M L Perille & Martin Collins in honor of Laura Krummenacker  
Mildred McFelea in honor of 2007 birthday's for the Carroll children  
Note Card fundraiser  
Christopher Fetta in honor of Laura Krummenacker  
Jack Reid in honor of Joyce & Ian Reid  
Kent & Laurie Smith in honor/memory of Mitchell Smith/Roman Fiore  
Caroline Trooboff in honor of the Hughes family  
Mildred MacKenzie  
Floyd & Jean Lane in honor of Alex Weaver  
Dan & Vicki McLellan in honor of Kacy Wyman  
John Matthews in honor of Shea Hammond  
West Bloomfield Township Employees in honor of Jack Greeley  
Tim & Jen Wyman/Center of Financial Planning in honor of Kacy Wyman  
Sandra Adams/Center of Financial Planning in honor of Kacy Wyman  
Dale & Corinne Parker/Center of Financial Planning in honor of Kacy Wyman  
Lori Stec in honor of Kacy Wyman  
Craig & Jen Riesch in honor of Bailey Riesch  
Beth & James Houtz in honor of Deborah Houtz request in lieu of Christmas gifts for her  
Ilene & Robert Darbee in honor of Kacy Wyman  
Wanda & Jim Birch in honor of Alex Weaver  
Gary & Becky Newcomb in honor Kacy Wyman  
Mary Garrett/Faculty and PTA of Pelham Rd in memory of Jennifer Scharf  
Gail & Jack Potts in memory of Deanna Lynn Potts

### Contributors (\$50 - \$99)

Lamar & Dot Davis in honor of Channing O'Halloran  
William & Louella Hatheway in honor of Jack Greeley  
Corwin & Wendy Will  
Allison Bolman in honor of Jack Greeley  
Terry Lubotsky in memory of Jennifer Scharf  
Kost & Candy Elisevich in honor of Kacy Wyman  
Burgess, Freeman & Parham, PA in memory of Jennifer Scharf  
Elva Smith in honor of Mitchell Smith  
Dave & Mary Ann Egnatuk in honor of Kacy Wyman  
Dan & Vicki McLellan in memory of Warren Gaymer  
Joyce Cease in honor of Deborah Houtz  
Jane Gross in honor of Sandy Glaize,  
Elizabeth Carlson & Nan Carrick  
Joel & Virginia Weinberg in honor of Jack Greeley  
Carol Bigelow in honor of Mitchell Smith  
Dr. Mark Frizzo in memory of Bernard Puma  
Elaine Kend in honor Jack Greeley  
Lois Pfeiffer in honor Kacy Wyman  
James Reposa

### Friends (up to \$49)

David & Vicki Borman in honor of Mason Reed  
Clinton Moore in honor of Chandler Moore  
Judy Sopeland & Charles Winslow in memory of Donna Morrill  
Dennis Hammond in honor of Jack Greeley  
Carol Nelson in honor of Jack Greeley  
T. Shaia in honor of Alex Weaver  
Tim & Jen Wyman in honor of Kacy Wyman  
Upstate Paralegal in memory of Jennifer Scharf  
Greater Greenville Association of Realtors in memory of Jennifer Scharf  
Mary Anne & John Reed in memory of Jennifer Scharf

The Cystinosis Research Network, Inc.  
302 Whytegate Ct.  
Lake Forest, IL 60045  
1-866-276-3669 (toll free), 1-847-735-0471  
847-235-2773 (fax)  
www.cystinosis.org



Cystinosis Research Network

---

*When moving, please remember to notify the Cystinosis Research Network of your new address. We do appreciate it!*

## Mark Your Calendars for Upcoming Conferences!

### **July 19-21, 2007**

The Cystinosis Research Network Family Conference at the Hotel Contessa in San Antonio, Texas. For more information, visit [www.cystinosis.org/conferences.html](http://www.cystinosis.org/conferences.html)

### **August, 2010**

International Pediatric Nephrology Meeting in New York City. More information will be on [www.cystinosis.org](http://www.cystinosis.org) as the event gets closer.