

Searching for a cure



Cystinosis Research Network

# Cystinosis Research Network Newsletter

HOPE through Research, Education, & Family Support

## Fall/Winter 2007

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## 2007 Cystinosis Research Network Family Conference Sets New Records

By Christy Greeley

**“Searching for a cure....Deep in the Heart of Texas”** - The 2007 Cystinosis Research Network Family (CRN) Conference was held July 19-21 in San Antonio, Texas. Prior to the start of the family conference, the CRN Scientific Review Board convened to review this year's collection of grant proposal submissions on July 18, 2007. The Cystinosis Research Network is dedicated to supporting and advocating research to help achieve its vision of the discovery of improved treatments and ultimately a cure for cystinosis. CRN currently supports six research grants in the U.S. and Europe totaling over half a million dollars in committed research funding. The CRN Executive Board reviewed the recommendations of the Scientific Review Board and made its funding decisions for new grants. —continued on page 13



Motivational Speaker Shad Ireland and Dr. David Ivey

Children and adults with cystinosis at the 2007 CRN Family Conference

### 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.



Speaker Ranjan Dohil, M.D., discusses the relationship between Gastrointestinal Issues and Cystinosis



The CRN Board of Directors—back row l. to r.: Dan Julian, John Shepperd, Elva Smith, Dave Greeley, Carol Hughes. 2nd row: Sandy Glaize, Karen Gledhill, Frankie McGinnis, Lynn Thomas, Mack Maxwell, Paula Shal. 1st row: Marybeth Krummenacker, Brittney LeBeau, José Morales, Pam Woodward, Christy Greeley.

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## Message from the President Christy Greeley

This is my first President's Message to our community and as I put "pen to paper" I am amazed at the journey my family has experienced to arrive at this point. I feel truly honored and blessed to assume these responsibilities and commit to each of you to perform my duties to the best of my abilities.

For many of you our story is very familiar -- for others it is not, but I believe it is important to understand why the Greeleys are so committed to the Cystinosis Research Network. Soon after my son, Jack, was diagnosed with cystinosis, I knew that I would become involved in the cystinosis community. My background in medical/pharmaceutical research and public health prepared me well for the challenges facing our family and CRN. My husband, Dave, and I were fortunate to meet the founders of CRN, Colleen and Jack Hammond and many others in 2001, only months after Jack's diagnosis. I was immediately impressed by their dedication, resourcefulness, and ability to embrace new thinking in order to move forward towards their goals. Dave and I soon became involved with CRN's Board, Dave assisting with marketing needs and me serving as Research Committee Chairperson, then as Vice President of Research, and most recently, as Executive Director and President.

I have been honored to work with an ever-expanding circle of dedicated parents, grandparents, extended family and friends, and individuals with cystinosis in our efforts to achieve our shared vision -- to educate families and the public and to find improved treatments and ultimately a cure for cystinosis. In particular, I'd like to thank José Morales for his leadership and vision as President over the past five years. I am committed to building upon the foundation created under his direction and continue to elevate our ability to influence and direct our own destiny. It is through the efforts of so many selfless individuals who have served on CRN's Board and its committees that so much has been accomplished in the six years since my son was diagnosed.

Mahatma Gandhi said, "Be the change you wish to see in the world." It is my personal goal that during my term as President I can inspire and lead CRN towards the embodiment of that sentiment -- that we as a community can make the changes we wish to see in the world of cystinosis through active engagement and focused determination.

2007 has been a monumental year for CRN. A few highlights from the last six months include:

- 2007 CRN Family Conference held July 19-21 in San Antonio, Texas
- CRN awards two new research grants as a result of July Scientific Review Board review meeting
- CRN announces establishment and funding of Cystinosis Fellowship at the National Institutes of Health under the direction of Dr. Bill Gahl
- The Harry A. and Margaret D. Towsley Foundation awards CRN with a matching grant of \$150,000
- CRN designated as the lead non-profit organization for the 2010 International Pediatric Conference to be held in New York City under the direction of Dr. Frederick Kaskel

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We continue to expand our reach and efforts to have an impact and these achievements offer tangible evidence of our success. More detailed updates and information can be found within this newsletter regarding these and many other accomplishments by the Research, Family Support, Education and Awareness and Development committees.

The 2007 CRN Family Conference represents the culmination of two years of planning by CRN's Conference Planning Committee. Our aim is to execute CRN's mission through the conference – to support and advocate research, provide family assistance and educate the public and medical community about cystinosis. I think everyone in attendance would agree this goal was achieved....in fact we exceeded our goal aspirations. Our Conference Planning Committee is to be commended for the many months of hard work:

Co-Chairs:	Marybeth Krummenacker, Christy Greeley, Pam Woodward, and John Shepperd
Conference Marketing:	Pam Woodward and Marybeth Krummenacker
Site Planning:	John and Kim Shepperd
Speaker/Advisory Board:	Christy Greeley and Elva Smith
Welcome/Registration:	Frankie McGinnis and Pam Woodward
Sponsorship:	Mack Maxwell
Agenda:	Christy Greeley and Marybeth Krummenacker
Day Care:	Pam Roesler
Budget:	Brittney LeBeau

We were fortunate to have many of the world's leading experts on cystinosis in attendance at the conference. They participated as speakers, workshop facilitators, poster session presenters, panelists, and researchers. We extend to them a sincere thank you for their generous dedication of time and contributions to make this year's conference a success. All information from the conference, including the agenda, speaker presentations, poster session abstracts, speaker lists and biographies, photographs and more can be found on the CRN website; [www.cystinosis.org](http://www.cystinosis.org). We have already assembled our committee for 2009, and we hope each of you make a commitment to join us in Atlanta, Georgia, the summer of 2009!

I look forward to serving the next three years as your President and extend an open invitation for you to reach out to me or Board Members with any comments or questions. We welcome anyone who would like to get involved on any of CRN's committees or as a board member. Please contact us at [crn@cystinosis.org](mailto:crn@cystinosis.org).

Warmest regards,  
Christy Greeley  
President



*José Morales, Marybeth Krummenacker, Dr. William Gahl, Mary Gahl, and Christy Greeley attended the National Organization for Rare Disorders (NORD) annual banquet in May 2007. Jose, Marybeth and Christy were honored to represent CRN to support Dr. Gahl, who received the Public Health Leadership award during the event. This banquet is an annual tribute to honor members of Congress, medical researchers, pharmaceutical firms, and others who have directly improved the lives of people affected by rare diseases.*

## CRN Financial Update

### By Brittney LeBeau, Treasurer

Below are CRN's major committees and the percentage to income each has expensed from January 1 to September 1, 2007. Total Assets and Total Income reflect the overall liquidity of CRN and the funds brought in to date, respectively.

<b>Assets=\$211,184.02</b>	
<b>Total Income=\$214,074</b>	
<b>Expenses:</b>	<b>% to Assets</b>
Development	<1%
Family Support	<1%
Education & Awareness	10%
Secretary	<1%
Research	35%
Executive Director	4%
Treasurer	1%
2007 Medical & Family Conference	30%
Total Committee Expenses to date	50%
Total Expenses w/ Conference	80%

## CRN Education & Awareness Update

### By Paula Shal, Vice President, Education and Awareness

My name is Paula Shal, and I have been on the CRN Board since 2005. I was recently elected Vice President, Education and Awareness at the 2007 CRN Family Conference. At the age of 17, I was diagnosed with cystinosis and have had three kidney transplants. I feel very blessed to have received three living related donors—my mom, my brother, and most recently, my husband, Jim. I work full time in a corporate training environment. Jim and I have three spoiled Yorkies. I initially became involved in CRN because I was so impressed with the way the organization ran, and I wanted to do something so that children with cystinosis could grow up without the health issues I have as an adult with cystinosis.

The Education and Awareness Committee is responsible for maintaining the CRN website ([www.cystinosis.org](http://www.cystinosis.org)), developing the bi-annual newsletter, ensuring CRN is represented at medical and genetic conferences, and selecting recipients of annual academic scholarships. In May, 2007, CRN was represented at the American Society of Pediatric Nephrology meeting in Toronto, Canada. In September, Marybeth Krummenacker represented CRN at the National Organization for Rare Disorders (NORD) Annual Conference.

My emphasis as VP Education and Awareness will be on finding ways to continue to educate adult nephrologists about cystinosis and to get them more involved in the cystinosis community. To help achieve that goal, CRN is planning to have a presence at the following conferences and/or meetings in 2008:

- Genetic Alliance Conference, July 11-13, Bethesda, MD
- American Society of Nephrology (ASN), Nov. 4-9, Philadelphia, PA
- National Organization for Rare Disorders (NORD) Annual Conference, September, 2008

CRN's visibility in the medical community will move us closer to our vision of improved treatments and ultimately a cure for cystinosis.

# Cystinosis Research Update

**By Elva Smith, Vice President, Research**

As the newly elected Vice-President of Research, I would, first of all, like to take this opportunity to express my sincere thanks to the members of the Cystinosis Research Network, CRN, for offering me the opportunity to be a part of this wonderful organization. I truly appreciate your confidence in me, and I can only promise that I will strive to be a positive presence on the Board of Directors and a productive member of the Research Team.

I am so impressed with what CRN has accomplished in the many arenas that it encompasses: Development, Education and Awareness, Family Support, Research; all backed by the hard work of our President, Executive Director, Secretary, Treasurer, and **YOU!** The saying is "*It takes a village to raise a child*", and I say it takes all of us in CRN to brighten the future for everyone dealing with cystinosis.

CRN sponsored research has made great leaps forward. From a commitment of just \$155,000.00 in the winter of 2005, we have expanded to a commitment of \$750,000 in research grants as of September 2007. That's nearly a 400% increase in two years! Thank you all for your part in making it possible!!

I am pleased to inform you that Sigma Tau continues to be committed to securing FDA approval for the cysteamine eye drops. CRN has been in frequent communications with Sigma Tau regarding the much anticipated cysteamine eye drop approval. Sigma Tau has indicated the eye drop NDA (New Drug Application) is in the midst of review and they are very optimistic approval will be obtained once questions and comments raised during the FDA review are addressed. As with any government process, nothing can be guaranteed and it is impossible for Sigma Tau to commit to a specific date the approval will be secured. CRN is committed to support Sigma Tau in any capacity to expedite the process. We will keep the community updated with any material progress.

The Call for Research Proposals was issued last Spring and the Scientific Review Board met in July during our biannual family conference in San Antonio. As a result of the recommendations from that meeting, CRN has granted funding to the following two research studies:

## **"Gene transfer studies for cystinosis"**

**Vasiliki Kalatzis, Ph.D., Eric J. Kremer, Ph.D., Institut Genetique Moleculaire de Montpellier, France**

**Grant Timeline: Fall 2007- Fall 2009**

**Award Amount: 75,900 € (approximately \$101,000)**

The aim of our work is to explore the possibility of alternative treatments for cystinosis using viral mediated gene transfer. This strategy has been successful in numerous preclinical cases of defective lysosomal hydrolysis but has never been used for correcting defective lysosomal transport. Rather than a multisystemic approach, we are initially concentrating on targeting the ocular and CNS anomalies in our animal model (*Ctns*<sup>-/-</sup>mice). Our recent data suggests that the ocular anomalies in *Ctns*<sup>-/-</sup> mice closely resemble those of patients. Furthermore, for the first time, we have brought to light marked age-related spatial and working memory defects in *Ctns*<sup>-/-</sup> mice, similar to those described in patients. There will never be one viral vector that can treat all tissues equally well thus we propose to compare the efficiency (in terms of titre, tropism and transduction) of two viral vectors, which can effectively transduce different tissues of the eye and CNS: a helper-dependent (HD) canine adenovirus (CAV-2) and an adeno-associated virus vector (AAV-8). Aside from the fact that these vectors are capable of long-term gene expression in the absence of toxicity, each efficiently transduces the cornea and multiple CNS structures. To complement the targeted gene transfer studies, we will compare the efficiency of cystine clearance in the CNS with that of cysteamine. Taken together, this work will use the sole-existing cystinosis animal model to further the understanding of the pathogenesis of cystinosis, and to develop an alternative long-lasting treatment that treats the cause of the disease rather than the symptoms.

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# Cystinosis Research Update

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## **“Evaluation of Novel Prodrugs for the Treatment of Nephropathic Cystinosis”**

**Professor Donald Cairns, Dr Rachel M Knott, Dr Graeme Kay**

**Grant Timeline: Fall 2007 - Fall 2008**

**Award Amount: £ 35,000 (approximately \$70,000)**

Recent work in our laboratories has concentrated on the design, synthesis, and evaluation of novel prodrugs for the treatment of nephropathic cystinosis. These agents are designed to be an odourless, tasteless, oral therapy which could allow once or twice daily dosing.

As a result of support from CRN and others we have synthesized > 50 candidate compounds and now seek funding to evaluate the ability of these compounds to deplete levels of intracellular cystine. The particular aims of the proposal are to fulfill the following objectives:

- Determine the level of oxidative DNA damage in cystinotic and non-cystinotic fibroblasts at baseline and in conditions of oxidative stress.
- Evaluate the effect of novel prodrugs on the intracellular distribution of cystine and the level of oxidative DNA damage in cystinotic and non-cystinotic fibroblasts.
- Develop a CTNS antisense model using non-cystinotic fibroblasts.

These studies will be carried out in the recently refurbished cell culture suite at RGU and will make use of a novel HPLC assay for intracellular thiols developed in-house. The work may be achieved within a period of three years.

In addition to these two studies, CRN is currently funding the following six research studies:

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

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

**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 Rabiou, 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)**

**Total current CRN grant funding = \$729,448**

The abstracts for these studies can be found at [www.cystinosis.org](http://www.cystinosis.org).

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## Cystinosis Research Update

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I am also pleased to share with you that Dr. Jess G. Thoene's "Tissue Repository for Cystinosis" project has been granted an unlimited time extension for the funding that he has previously been granted. Occasionally research moves along at a pace different from that which was initially anticipated and can also be impacted by unexpected events, in this case hurricane Katrina. In May, 2007, Dr. Thoene submitted the following progress report on his tissue repository project:

In compliance with the terms of the award CRN made to me for the project titled " Tissue Repository for Cystinosis", I submit the following:

- 1) Funding was received at the University of Michigan on 12/1/06. As you know, significant paperwork was required on my part to comply with University requirements to transfer the existing, though unfunded, grant from Tulane to here.
- 2) IRB approval was required. This consumed substantial effort and three revisions before approval was received on Feb 15, 2007. CRN was instrumental in providing letterhead copy of the sample recruitment form for IRB review. In the approved version I am not required to obtain informed consent to receive the existing samples, but am therefore precluded from direct contact with parents and children on this issue. They contact their nephrologist or pathologist and ask that physician to contact me to arrange shipment of coded specimens. I then ship it to Dr Walker for analysis.
- 3) CRN sent the recruitment letter to its membership.
- 4) Thus far, I have received one coded sample and have sent it to Dr. Walker in Little Rock , AR for analysis.
- 5) I am grateful for the patience and support of CRN and look forward to having data to share with you at the 12 month report.

I would also like to draw your attention to a recent publication by Vasiliki Kalatzis, et al that cites CRN and was partially funded by CRN: *The Ocular Anomalies in a Cystinosis Animal Model Mimic Disease Pathogenesis*. The article was published in [Pediatric Research](#), Vol. 62, No. 2, 2007.

**ABSTRACT:** Cystinosis is a lysosomal storage disorder characterized by abnormal accumulation of cystine, which forms crystals at high concentrations. The causative gene *CTNS* encodes cystinosin, the lysosomal cystine transporter. The eye is one of the first organs affected (corneal lesions and photophobia in the first and visual impairment in the second decade of life). We characterized the ocular anomalies of *Ctns*<sub>/</sub><sub>-</sub> mice to determine whether they mimic those of patients. The most dramatic cystine accumulation was seen in the iris, ciliary body, and cornea of *Ctns*<sub>/</sub><sub>-</sub> mice. Consistently, *Ctns*<sub>/</sub><sub>-</sub> mice had a low intraocular pressure (IOP) and seemed mildly photophobic. Retinal cystine levels were elevated but increased less dramatically with age. Consistently, the retina was intact and electroretinogram (ERG) profiles were normal in mice younger than 19 mo; beyond this age, retinal crystals and lesions appeared. Finally, the lens contained the lowest cystine levels and crystals were not seen. The temporospatial pattern of cystine accumulation in *Ctns*<sub>/</sub><sub>-</sub> mice parallels that of patients and validates the mice as a model for the ocular anomalies of cystinosis. This work is a prerequisite step to the testing of novel ocular cystine-depleting therapies.

The publication can be found in its entirety on the cystinosis website [www.cystinosis.org](http://www.cystinosis.org) .

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## Cystinosis Research Update

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CRN was pleased to announce at the 2007 Family Conference the establishment of a fellowship at the National Institutes of Health under the supervision of William A. Gahl, MD, PhD, of the National Human Genome Research Institute. He will train an expert in nephropathic cystinosis at the National Institutes of Health. Optimally, the fellowship training would follow a renal fellowship, last approximately 3 years, and provide a springboard to an academic career in cystinosis and related fields. This is not a service position; it is intended to provide the next generation with an authority in the disease. The successful candidate will work primarily on cystinosis, but may also perform research into related disorders with renal manifestations. The Cystinosis Research Network will support this fellowship entirely through an NHGRI Gift Fund.

Dr. Bill Gahl, Ziggy Balog and Dr. Robert Kleta have recently published a very timely article on cystinosis in adults. As you know, we have quite a few adults with cystinosis in our extended cystinosis family, and now that we, thankfully, have the benefit of treating our children with cysteamine (better known as Cystagon to most of you) as soon as they are diagnosed we can look forward to an ever-expanding "adult" world of cystinosis. A brief outline of the article, which was published in *Ann Intern Med.* 2007;147:242-250. [www.annals.org](http://www.annals.org) follows, and the complete article can be found on our website.

**Nephropathic Cystinosis in Adults: Natural History and Effects of Oral Cysteamine Therapy**, by William A. Gahl, MD, PhD; Joan Z. Balog, RN, MSN; and Robert Kleta, MD, PhD

**Background:** The full burden of nephropathic cystinosis in adulthood and the effects of long-term oral cysteamine therapy on its nonrenal complications have not been elucidated.

**Objective:** To assess the severity of cystinosis in adults receiving and not receiving oral cysteamine therapy.

**Design:** Case series.

**Setting:** National Institutes of Health Clinical Center.

**Patients:** 100 persons (58 men and 42 women) age 18 to 45 years with nephropathic cystinosis examined between January 1985 and May 2006.

**Measurements:** Historical data were collected on renal transplantation, administration of oral cysteamine, and time and cause of death. Patients were evaluated for height and weight; thyroid, pulmonary, and swallowing function; muscle atrophy; hypogonadism (in men); retinopathy; vascular and cerebral calcifications; diabetes mellitus; and homozygosity for the common 57-kb deletion in *CTNS*. Laboratory studies were also performed.

**Results:** Of 100 adults with nephropathic cystinosis, 92 had received a renal allograft and 33 had died. At least half of the patients had hypothyroidism, hypergonadotropic hypogonadism (in men), pulmonary insufficiency, swallowing abnormalities, or myopathy. One third of the patients had retinopathy or vascular calcifications, and 24% had diabetes. Homozygosity for the 57-kb *CTNS* deletion was associated with an increased risk for death and morbidity. The 39 patients who received long-term (8 years) oral cysteamine therapy were taller and heavier, had a renal allograft later in life, had lower cholesterol levels, and experienced fewer complications and deaths than patients who received cysteamine for fewer than 8 years. The frequency of diabetes mellitus, myopathy, pulmonary dysfunction, hypothyroidism, and death increased as time off cysteamine treatment increased, and it decreased as time on cysteamine therapy increased.

**Limitations:** The study was retrospective and not randomized. The criteria used to measure adequacy of treatment were arbitrary.

**Conclusions:** Untreated nephropathic cystinosis causes extensive morbidity and death in adulthood. Long-term oral cysteamine therapy mitigates these effects.

# 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).*



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## **~ 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 you 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.

*The Cystinosis Research Network is an all-volunteer, non-profit 501(C)3 organization, Federal Tax ID # 04-3323789.*

# Cystinosis Research Update

## New Fellowship Program Announced in Ireland



### Molecular Medicine Ireland

Dr Ruth Barrington, Chief Executive of the Dublin Molecular Medicine Centre, today (1 November 2007) announced the launch of a prestigious new Fellowship Programme to train the next generation of academic medical leaders in Ireland. The first intake of the *Molecular Medicine Ireland Clinician Scientist Fellowship Programme* will comprise at least 22 Fellows competitively selected from medical graduates at registrar level who wish to undertake PhD training. The Fellowship Programme, which has received funding of €11m from the Higher Education Authority under the *Programme for Research in Third Level Institutions*, will be organised on a national basis by Molecular Medicine Ireland<sup>1</sup> and delivered by the participating institutions: National University of Ireland, Galway, Royal College of Surgeons in Ireland, Trinity College Dublin, University College Cork and University College Dublin.

Commenting on the significance of the programme, Dr Barrington said that 'This programme is one of the most important advances in Irish medical training. Until now, medical graduates who wished to pursue a career in research often had to do so abroad. This programme gives some of our best medical graduates the opportunity to train to the highest standards as clinician scientists in Ireland.'

Dr Michael Kamarck, Chair of the Dublin Molecular Medicine Centre, welcomed the initiative, 'this training programme transcends institutional boundaries to give Fellows unparalleled access to the top biomedical researchers in the country, and to state-of-the-art basic and clinical research facilities. It will also attract to Ireland high calibre medical graduates who wish to undertake their training in this well structured programme, and it will build Ireland's international reputation in biomedical research.'

The Fellowship programme will address one of the key challenges of modern medicine – how to speed up the translation of advances in research into more effective ways of preventing and treating disease. The Fellows will undertake their research in areas in which Irish universities and academic

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<sup>1</sup>Molecular Medicine Ireland (MMI) is a not for profit company being established by National University of Ireland, Galway, Royal College of Surgeons in Ireland, Trinity College, University College Cork and University College Dublin. to achieve their common objectives in accelerating the translation of scientific research into better quality outcomes for patients. MMI will build on and replace the Dublin Molecular Medicine Centre.

# Cystinosis Research Update

continued from page 10

hospitals are strong; such as neuroscience, infection and immunity, cancer, regenerative medicine, respiratory medicine, and cardiovascular disease. Each medical graduate in the programme will bring his or her clinical expertise into the laboratory in their host university/college and have the opportunity to train in depth in a relevant area of biomedical research. The Fellows will come together for part of their training, developing their experiences beyond any single laboratory or institution. The Fellows will be selected by a competitive process organised by Molecular Medicine Ireland, involving their sponsoring institutions and a cross-institutional panel including international experts.

The introduction of this Fellowship implements a recommendation of the Report of the Strategic Advisory Committee, ***Towards Better Health – Achieving a Step Change in Health Research*** (2006) available at the following link [http://www.sciencecouncil.ie/reports/acsti061123/forfas061123\\_acsti\\_health\\_research\\_full\\_report.pdf](http://www.sciencecouncil.ie/reports/acsti061123/forfas061123_acsti_health_research_full_report.pdf)

Further information on the programme is available at [http://www.dmmc.ie/MMI\\_Clinician\\_Scientist\\_Fellowship.htm](http://www.dmmc.ie/MMI_Clinician_Scientist_Fellowship.htm)



## 5th International Cystinosis Conference Set to Take Place in Dublin, Ireland

The 5th International Cystinosis Conference will take place in Dublin, Ireland on June 27-28, 2008. World experts in the field of cystinosis as well as researchers, families and patients will be in attendance. A comprehensive program is being created to include the presentation of the latest research in cystinosis as well as sessions for professionals, families and patients. Up to date information will be available on [www.cystinosis.ie](http://www.cystinosis.ie).



## 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

\*\*\*\*\*

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

### **Academic Achievement in Cystinosis and Cystic Fibrosis**

The UCSD Pediatric Neurology Research Group is conducting a study to examine academic achievement, which includes skills such as reading, writing, and arithmetic, in individuals with cystinosis or cystic fibrosis. Participants will include individuals with cystinosis or cystic fibrosis ages 5 years through 18 years. This study will involve approximately three 2- to 2 ½-hour cognitive-behavioral testing sessions. The testing will help us learn more about academic achievement in cystinosis and cystic fibrosis. Participants and/or teachers will also be asked to fill out questionnaires regarding school behaviors. Participation in this research study is completely voluntary.

If you would like to participate in the Academic Achievement study or if you would like more information, please contact Kirsten Kung at UCSD: [kpoehlmann@ucsd.edu](mailto:kpoehlmann@ucsd.edu) or 858-822-6800.

## Participants Sought for Cystinosis Research

Dear Families,

Drs. Schneider and Fidler are conducting a research study to learn more about how to prepare the blood samples used for the determination of white blood cell cystine levels.

For this study, they are looking for cystinosis patients (12 years and older) who would travel to San Diego for this study.

Flight cost will be paid for. Preference will be given to patients 18 years and older, who can fly to San Diego and back home on the same day.

Patients do not have to currently be taking Cystagon.

Patients have to be able to provide recent laboratory test showing that their red blood cell count is not below normal.

White blood cell cystine levels need to be measured occasionally to be certain patients are taking the correct dose of Cystagon. When we started to study cysteamine many years ago we tried to find a way to have whole blood shipped to our laboratory so that we could both prepare the white blood cells and measure the cystine. We couldn't make this work. We only got reliable results if the white blood cells were made promptly after the blood was drawn.

Although preparing the white blood cells is not very difficult, it is very time consuming and labs often find the preparation challenging, especially if a lab only does this every few months. We have some ideas of how we might stabilize the white blood cells so that the blood could be shipped and our laboratory could prepare the white blood cells. To test these ideas we need some cystinosis patients who are willing to donate blood. Patients volunteering for this study will be asked to come to the UCSD (University of California, San Diego) Medical Center in San Diego where a blood sample will be taken. Depending on the age and blood count of the patient, up to 10 tablespoons of blood will be taken (150 mL). A <sup>3</sup>unit<sup>2</sup> of blood that is taken at a blood bank is three times as much (450 mL). Of course smaller patients will have less blood taken. Patients may be asked to not take Cystagon for 24 hours before the blood draw.

Participating in research is entirely voluntary.

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).

Thank you!

--

Meredith C Fidler, PhD

Asst. Project Scientist  
Pediatric Gastroenterology and Nutrition  
UCSD Medical Center  
200 West Arbor Drive, MC 8450  
San Diego, CA 92103-8450

Phone (619) 543 2049  
Fax (619) 543 7537

# Participants Sought for Cystinosis Research

## Participate in UCSD's Cognitive and Neural Development Study

**How does your brain choose important sights and sounds from the environment?  
What goes wrong with cystinosis?**

We are looking for healthy individuals, as well as those with cystinosis, 6 to 45 years of age, from all language backgrounds.

### **What is the study about?**

This study is to help us understand how the auditory and visual systems function in people with cystinosis and what the origin of late-onset brain damage is.

### **How do we conduct the study?**

There are two 2-hour sessions, during which we record the participant's brain waves while they "play a computer game." In one session, the participant looks at a computer screen and presses a button once a certain image is presented in a designated location. During another session, the participants will attend to sounds presented through several speakers and will press a button every time they hear a specific sound.

Recording the activity of the brain is non-invasive, completely painless, and safe. (In rare cases, there may be some mild skin irritation). This method is widely used in child and adult research. The participants wear a special hat with the sensors of electrical brain activity plugged into it. Our participants sit in a comfortable chair in a soundproof booth while playing the game.

The identity of you or your child, as well as of all data records, is entirely confidential.

### **What are the benefits of participation?**

For participating, children and adults will receive \$20 per session. Children will also receive a small toy as incentive.

### **How do I schedule a session?**

To schedule a session or for more information, please contact:

Mikeala at (858) 822-1961, [mkinnear@ucsd.edu](mailto:mkinnear@ucsd.edu)

Applied Physics and Mathematics bldg. Prime  
9500 Gilman Dr.  
LaJolla, CA 92093-0113  
<http://www.crl.ucsd.edu/pcnd>

Funded by the Cystinosis Research Foundation

## 2007 CRN Family Conference

*Continued from page 1*

Several important announcements were made during the conference, including:

### **Governance**

Successful transition of CRN leadership as new Executive Committee members were elected at annual Board of Directors meeting:

- Christy Greeley, President
- Elva Smith, Vice President, Research
- Jill Morrill, Vice President, Development
- Paula Shal, Vice President, Education and Awareness
- Karen Gledhill, Secretary
- Brittney LeBeau will continue her current term as Treasurer and Pam Woodward will continue her current term as Vice President, Family Support.
- José Morales, Marybeth Krummenacker, John Shepperd, Frankie McGinnis, Lynn Thomas, Carol Hughes, Sandy Glaize, Kathy Harrison, Dave Greeley, Dan Julian, and Mack Maxwell will continue in their current terms as Directors on the CRN Board.

### **National Institutes of Health Cystinosis Fellowship**

CRN announced it will establish and financially support a three year clinical and research fellowship under the direction of Dr. Bill Gahl at the National Institutes of Health in 2008.

### **International Pediatric Nephrology Conference**

CRN announced it has been designated as the lead non-profit organization for the 2010 International Pediatric Nephrology Conference in New York City, which will include major sections focusing on cystinosis. The conference is being organized under the leadership of Dr. Frederick Kaskel.

### **Future Family Conferences**

Future CRN family conference sites were named, including:

- 2009 - Atlanta, Georgia
- 2011 - San Francisco Bay Area, California



*Laura Krummenacker, Laura McGinnis, Amelia Douglas, Victor Gomez, Shannon Paju, Heidi Hughes, and Briana Smythe*



*Rodney, Tammy, and Gabe Stephenson*

*Continued on page 16*

## 2007 CRN Family Conference

*Continued from page 15*

The hugely successful family conference included the following highlights:

### **Attendance**

Record attendance of over 300 family members, physicians, researchers, and professionals.

### **Research Studies**

Two cystinosis research studies were available for participation and were conducted concurrently with the Family Conference:

- Neurological testing by Dr. Doris Trauner's team from UCSD
- Blood sample collection by Dr. Katy Freed and Dr. Eric Moses's team from the Southwest Foundation for Biomedical Research in San Antonio for a study that will examine the genetic pathway(s) associated with the cystinosis gene. CRN received the following letter of thanks to the cystinosis community:

*"Could you please pass on our thanks and gratitude to all those family members who took the time (and pain!) to donate blood samples for our research. We feel that we have generated an extremely important resource, not only for our research projects, but also other researchers wishing to collaborate and make use of this sample bank."*

*-- Dr. Katy Freed*

### **Motivational Speaker**

Shad Ireland, the first dialysis patient to ever compete in and complete an ironman triathlon, kicked off the proceedings by sharing his inspirational story of taking charge of our own destiny as patients and family members of those with chronic health conditions.

### **Innovative Poster Session**

An innovative poster session format was developed and conducted which showcased a mix of science, medicine, and advocacy group and patient experiences and provided an interactive experience for both family and professional attendees. Presenters were able to showcase their research, clinical experiences, advocacy group updates, and real patient and family experiences through poster presentations and other forms of display. Participation by the conference participants was high as the format created the opportunity for families to dialog with the representatives on a personal level.



*Shad Ireland and Garrett Thomas*



*Adults with cystinosis and Dr. William Gahl*

*Continued on page 17*

## 2007 CRN Family Conference

*Continued from page 16*

### **Orthotics**

Families were afforded the opportunity to receive free orthotics assessment and fitting. This was possible as a result of the compassion and generosity of Dr. David Ivey, a family practice chiropractor from South Carolina.

### **Medical Panel**

The Medical Panel and stage specific workshop sessions enabled participants to directly interact with the world's experts on cystinosis. The questions covered the entire spectrum of cystinosis: fundamental understanding of the disease, current available treatments, on-going research studies and what potential breakthroughs we might expect in the future.

### **Personal Support Network**

Professional and family relationships were formed and strengthened. The following excerpt comes from a thank-you note CRN received from one of the families who joined us in San Antonio summarizes the emotions we all felt as we left Texas:

*"The conference enables us to feel "normal" and it helps talking to doctors, families, and friends and learn of their everyday situations. It is a breath of fresh air to be around our "family"; others who know and have gone through all we have certainly helps us regroup and come up with new ideas to better our children...I don't think we can ever put into words the info and experience we take from the conferences and how enlightening it is for our family. Just know that without CRN, we don't think we'd be where we are today."*

For all those who were not able to attend, you were missed! All of the presentations and material covered during the conference will be available on our website at <http://www.cystinosis.org/conferences.html>. We are excited about the success of the Family Conference and hope all of you will be able to join us in Atlanta in 2009.



*The 2007 CRN Family Conference Medical Panel*

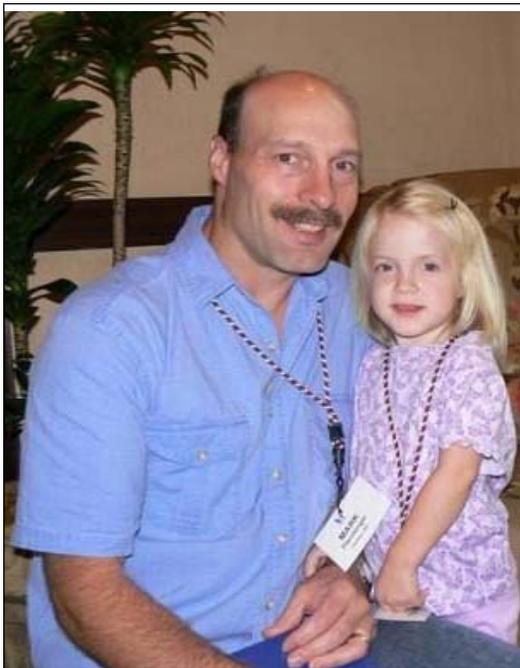


*Livia Stilke, Rachel Smith, Mason Stilke, and Mitchell Smith*

# 2007 CRN Family Conference



*Serge, Jennifer, and Madison Babineau*



*Mark and Tina Flerchinger*

CRN would like to thank the following individuals and organizations for making the 2007 CRN Family Conference possible:



- HEB
- Amfit Orthotics
- David English
- Dr. David and Diana Ivey
- Jefferson State Bank
- Konica Minolta
- Sarah Lemessurier
- T. Leopold
- J. Martinez III
- Milleridge Fundraiser
- Marilyn and William Moll
- Printing USA
- Shirley Schindler
- Alfred and Honey Shepperd
- John Ben Shepperd Estate
- Amy Stieren Smiley
- Towsley Foundation



*Child care coordinator Pam Roessler and the visiting clown*

## Cystinosis Mexico AC Update

By Victor Gomez

### The First Cystinosis Medical Training Course Held in Mexico City

The first Cystinosis Medical Training Course in Mexico City was held July 23-25 and August 1-3 in the National Medical Center Century XXI. It was the first cystinosis course that was completely spoken in Spanish. Nephrologists, pediatricians, nurses, and general physicians were in attendance. The purpose of this training course was to raise awareness of cystinosis in the medical community and to emphasize the importance of early diagnosis and cystinosis treatment. Here are some of the highlights of the training course:

- Natural history and classification of cystinosis
- Importance of early diagnosis
- Clinical issues and importance of ophthalmic evaluation
- Fanconi Syndrome, renal complications, and kidney transplants in patients with cystinosis
- Summary of activities and additional information presented by Mexican Association of Cystinosis
- Current cystinosis research report from the USA

The course included a test at the end, and physicians who completed the whole course presented Power Point presentations for the group.

This course was a huge step in raising cystinosis awareness in Mexico City!

**The Fifth Medical Cystinosis Symposium will take place in Mexico City in September, 2008. Stay tuned!**



*Physicians and nurses learn about cystinosis at the first Spanish-speaking Cystinosis Medical Training Course in Mexico City, Mexico.*

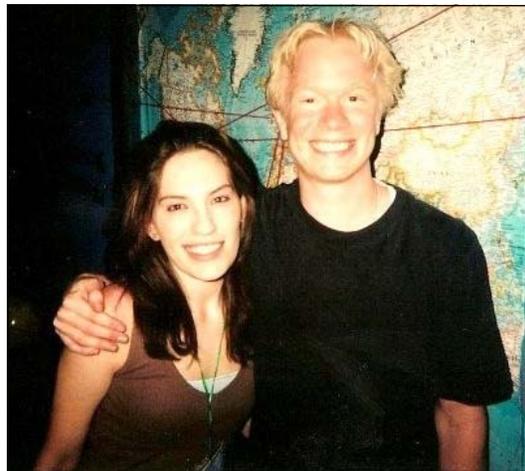
## 2007 CRN Scholarship Recipients

Steve Schleuder is the recipient of the 2007 CRN Scholarship for an individual with cystinosis who is pursuing a college education.

Dear CRN,

I received your message about the scholarship money. First of all I would like to say thank you very much for this scholarship, it will help quite a lot. I am currently attending Schoolcraft Community College and after two years, I plan to transfer to Central Michigan University. My goals currently are numerous. I plan within the next two years to take full responsibility of my adult life and all that it entails. This includes learning how to do the laundry (which I currently do very successfully) and cooking as well as ordering medicine, solo doctor visits, transferring from pediatric to adult doctors, and figuring out money issues for the future. This last goal may sound a little strange since I'm only 19 and just started college, but my circumstances, as you and many other people understand, are quite different than the average 19 year old. I am also making it a goal to job shadow numerous occupations in order to find my right path in life as well as find myself a temporary job to build up money and save this money for various needs in my life at present and for the future. My brother, Eric, is a financial planner and talked all the economics of my life over with me. This helped me quite a lot, and he promised that as long as either one of us was alive, he would help me. I thank the CRN again for selecting me for this honor.

Sincerely,  
Steve Schleuder



*Steve Schleuder and his friend, Renee*

### CRN Sierra Woodward Sibling Scholarship Recipients

Allison Tschannen and Kelly McCalla are the recipients of the CRN Sierra Woodward Sibling Scholarship awarded to a sibling of an individual diagnosed with cystinosis.

Allison Tschannen, 18, is the daughter of Terry and Barbara Tschannen and the sister of Weston Tschannen (with cystinosis). Allison graduated in the spring of 2007 from Brookfield R-III High School and is currently attending William Jewell College in Liberty, Missouri. Her major is English Language and Literature in the Oxbridge Honors Program.

Kelly K. McCalla, 21, is the daughter of John and Susie and the sister of Kevin McCalla (with cystinosis). Kelly is from Kerrville, Texas and is a Senior at The University of Texas at Austin majoring in Human Relations in the School of Communication.



*Allison Tschannen*

## Evan Monk's Sledge Hockey Team Wins Bronze

Evan Monk helped his team win a bronze medal in the Sledge Hockey Regional Para Olympic Games in April. Evan scored in the second period to tie the game 1-1. Then 5 minutes into the third period one of his teammates took a shot and got a tip-in taking the score to 2-1. Evan's team held the competition off until the end, even when the other team pulled their goalie and set an all out attack.

The team now holds the bronze medal for Ontario and will be competing in the National games in December. Unfortunately, Evan is having back surgery in June and will be off for a year. Evan is 21-years-old. His family is extremely proud of him.



*Evan Monk*

## Eddie Langley Competes on Hell's Kitchen

Eddie Langley, age 28, was selected as a contestant for the popular FOX reality show, Hell's Kitchen. Hell's Kitchen features twelve chefs all competing for a job in Chef Gordon Ramsay's latest restaurant venture. Chef Ramsay auditions the chefs with a tough, no non-sense approach. The show premiered on Monday, June 4. Unfortunately, Eddie was eliminated from the show on June 11, but he made the cystinosis community proud!

Eddie was diagnosed with cystinosis as an infant. He was featured in the Spring/Summer 2006 CRN newsletter. He recently provided more info about his Hell's Kitchen Experience.

**CRN:** Why did you decide to try out for Hell's Kitchen?

**Eddie:** *I knew I could keep up no problems and thought if I ever had the chance I would go for it, so I did.*

**CRN:** Did you watch the first two seasons of Hell's Kitchen?

**Eddie:** *Yes, I watched all the other episodes from previous seasons. I always thought I could do what they do but forgot about all the stuff we did not see on camera.*

**CRN:** What was the audition process like?

**Eddie:** *The auditions were sort of fun. The first night though I waited in line over 3 hours in very cold weather and forgot my jacket. Good thing dad came to support me after work. He had a jacket and would let me wear it and he would go sit in the car in the heat -LOL. Thanks dad!!*

**CRN:** How long were you involved in the experience?

**Eddie:** *I was probably there for a total of 4 or 5 days. I forget exactly.*

**CRN:** How did your friends, family, current employer, and co-workers react when you said you told them you were on Hell's Kitchen?

**Eddie:** *My friends were stoked, and my mom and dad were shocked. My employer at the time was in dismay but sort of snobbish towards me afterwards. They sort of felt indifferent about the whole thing. Since then I have started my own business and also expect another job at a 5 star resort.*

*Continued on page 22*

## Eddie Langley Competes on Hell's Kitchen

*Continued from page 21*

**CRN:** What was the best part of your Hell's Kitchen experience?

**Eddie:** *I think that I did keep up with everyone, and I know I could have won. I still have an open challenge to anyone on the show or anyone else for the matter (HA HA).*

**CRN:** What was the most challenging part of your Hell's Kitchen experience?

**Eddie:** *The lack of rest. We would wake up around 6am and work until after midnight. Then after that we still had confessions and interviews and stuff. We averaged about 3 hours of sleep a night.*

**CRN:** What was the greatest lesson you learned on Hell's Kitchen?

**Eddie:** *To be myself and let people know the real me. I wasn't going to be anyone's puppet, nope not me!!*

**CRN:** How did you feel when Rock selected you instead of Aaron for elimination?

**Eddie:** *Were you surprised? I was a little surprised yes. But it was the smart move. If I was not sent home, I would have won. The only thing I wish is that I said something different then what I did. That was the only time I did not say what was in my heart, or didn't speak my mind so to speak. That will never happen again.*

**CRN:** How did dealing with cystinosis affect your Hell's Kitchen experience? (Were you able to stay on medicine schedules? Did the bright lights bother your eyes?)

**Eddie:** *Cystinosis has nothing to do with it. I have had it all my life, so I ignore the fact. I always keep my mind on what needs to be done and not that which can hinder me. I always get very angry when someone makes excuses for things to hold them back or if something impairs them. I know we all have different stages of cystinosis, but don't let it stand in the way of your dreams. We will always have it. Who cares if were smaller or what not. We need to prove to the world we can run with the big dogs and beat them. We have been through so much and it takes a lot of heart to stay focused, and it makes us stronger. I could go on and on, but you get the picture.*

**CRN:** How did your cast mates react to the fact you had cystinosis?

**Eddie:** *I never told them I had cystinosis, just told them I have had 2 kidney transplants, er I think I might have. I did not go on the show to talk about my kidney problems. That was the furthest thing from my mind. I went on the show to cook.*

**CRN:** What advice would you give to others with cystinosis who want to go on a Reality Show or pursue any dream they may have?

**Eddie:** *Don't let anything stand in the way of your dreams. Work hard and don't give up. As far as reality TV goes, go for it if you want, but remember cameras are there 24/7, and they can edit anything they want...*

**CRN:** How has Hell's Kitchen impacted your life?

**Eddie:** *People seem to recognize me, and I have signed a few autographs, which is hilarious. I mean I was just lucky to get on a show. I am not a celebrity—LOL. On the professional side, people's expectations are through the roof, and I have to prove myself every day.*

**CRN:** Anything else you would like to tell us about your experience on Hell's Kitchen?

**Eddie:** *It was a fun experience, and I would do it again in a heart beat.*

## 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
Ongoing	Fundraising Letter Campaign	N/A	Mason & Livia Stilke
March 30, 2007	Ricardo, Inc. Jeans for a Cause	All U.S. Ricardo, Inc. Offices	Steve Schleuder
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	3rd Annual Golf Tournament	Colorado	Neveah Stanford
June 16, 2007	Lucas and Shane Wysocki's Birthday Party	Lucas and Shane's House	Jacob Ellerbrock
August 11, 2007	Roundup Parade Fundraiser	Vega, TX	Mason Reed
August 26, 2007	4th Annual Family Fun Day <a href="http://www.jacksfamilyfunday.org">www.jacksfamilyfunday.org</a>	Lincolnshire, IL	Jack Greeley
September 8, 2007	C.H. Robinson First Annual Cystinosis Golf Tournament	Lehi, UT	Tahnier Woodward
Month of October	Usborne Book Fundraiser	N/A	Carleigh DeCroce
October 12, 2007	2nd Annual Carnival for a Cure	Naperville, IL	Evan & Alexis LeBeau
October 19, 2007	Boys and Girls Club Dance	Illinois	In memory of Olivia Grace Medina
October 19-26, 2007	Eastside High School Wade Hampton Week	Greenville, SC	Laura McGinnis
November, 2007	Silpada Jewellery Fundraiser	<a href="http://www.mysilpada.com/jill.morrill">www.mysilpada.com/jill.morrill</a>	Megan Morrill
December 9, 2007	Cuts for Kacy	Birmingham, MI	Kacy Wyman

## CRN Development Update

**By Jill Morrill, Vice President, Development**

My name is Jill Morrill, and I am your new Vice President of Development for CRN. I live in Grand Rapids, Michigan and am married to Brian. We have two children, Megan and Tyler. Tyler is 8 years old and keeps us busy. He does not have cystinosis. Megan is 11 years old and was diagnosed with cystinosis about 9 years ago. We are so grateful to CRN and all their support, information, helpful hints, and hope for the future.

I have realized over the past years that Megan's future will remain bright. This is mostly because of successful fundraising. Any money raised really makes an incredible impact on our children and adults who suffer from this disease. Through fundraising we spread awareness out to the community, support our researchers, and find new hope for the future. We are a small community with amazing and dedicated doctors and families. Whether your fundraiser is on a large scale or just a simple holiday letter encouraging friends and family to give, it all adds up.

One of my goals for development is to put together a fundraising packet or site where we all can go for ideas. Where contact information is available from previous fundraisers with support and guidance to make yours successful. Why reinvent the wheel? We are here to help one another, so start thinking how you can spread awareness and monetary support to CRN.

A great way to get started is it to look at the fundraising calendar from our previous year and get ideas. Your child, close friend, and those families newly diagnosed with cystinosis will thank you tremendously. Just see what we are supporting right now! It is very exciting and we can do even more with your help. Our children depend on us for a healthy future.

Kacy Wyman's anniversary letter is included on the following pages as a great way for all of us to get started or try something new. Include fundraising for CRN as your New Year's Resolution for 2008, and feel free to contact me with any questions you may have regarding your upcoming fundraiser.



*Kacy Wyman and Alexis LeBeau at the NIH in October*



*Brittney LeBeau, Jen Wyman, Alexis LeBeau, and Kacy Wyman at the Children's Inn*

**Neveah Stanford Golf  
Outing Raises \$2500 for the  
Cystinosis Research Network!**

## Kacy Wyman's Anniversary Letter

### Surviving Cystinosis...one year later!

Dear Friends and Family,

September 2007 marked Kacy's first anniversary living with Cystinosis. It has been a year that has brought much change into our lives. It is a life run by the clock and controlled by medicine, but Kacy's personality and attitude have made it an easier transition than thought possible. In the last 12 months, thanks to the wonders of modern medicine and a very medically compliant little girl, Kacy's kidney function is good, her electrolyte levels are stable, she has grown 4.5 inches and gained 10 pounds. She feels better than ever.

In July Jen attended the Cystinosis Research Network Family Conference in San Antonio, Texas. It was an incredibly sobering and yet energizing experience. Jen learned, among many things, that having a child who lives with a rare disease has its medical advantages and disadvantages. That you can be both emotionally uplifted and emotionally drained at the same time. That there is a very small community of people who really understand what it means to raise a child with Cystinosis and that there is comfort in numbers, however small those numbers may be. It is not a disease that receives a lot of exposure and funding, so any amount raised makes a very large impact on a very small number of people. That the people affected with Cystinosis are incredibly strong and resilient. That the doctors and researchers are few in numbers but rich in heart and dedication.

As with any disease a cure is always the ultimate hope. We are not at that point yet, but the research possibilities are amazing. The Cystinosis Research Network is currently funding 8 studies. One of the most exciting involves the creation of an odorless, tasteless pro-drug form of cysteamine. This is the nasty medication that all Cystinosis patients take every 6 hours round the clock to keep Cystine levels in a normal range. The hope is that the medication will also eventually be altered to a state where patients will be able to take it every 12 hours instead of 6. That would be remarkable.

We have learned this year that one little person can change the way you live. We would do anything we could to take Cystinosis away from Kacy, but that isn't possible. All we can do is fight to make her quality of life the best it can be every single day. She has been a blessing in so many ways. We all have our own journeys. Some are easier than others. We believe Kacy has Cystinosis for a reason. Perhaps to make us all look a little differently at the way we live. Perhaps to remind us that living in the present is the only way to live...yesterday was a good day, today is moving along nicely, tomorrow is anyone's guess. Live in the moment...it's your only guarantee.

Research takes time and unfortunately a great deal of money. Since October, 2006, with your help and some amazing fundraisers, we have raised over \$70,000 for the Cystinosis Research Network. It is our hope that we can continue that trend. It is the only way we can be assured that continued progress will be made to finding a cure. On that note, if you find yourself searching for a charitable cause this giving season, we hope you will consider Kacy and the Cystinosis Research Network as an option. I promise, she's worth it. She was born to do great things.

As Always, Many Thanks and Much Love,

The Wyman Family

## Eastside High School Raises \$106,829!

*Eastside High School and arch rival Wade Hampton High School in Greenville, South Carolina compete in a fundraising event each fall called Wade Hampton Week. Each school selects a cause by giving community members an opportunity to present their charity. The Cystinosis Research Network has been the beneficiary of Eastside's fundraiser four times receiving over \$300,000 in donations from the fundraiser! Frankie McGinnis, CRN Board Member and Mom to Laura (with cystinosis) and Chris (without), has successfully lobbied for CRN to be Eastside's charity of choice.*

### Where is Your Future?

**By Frankie McGinnis**

I think that as a society we are inundated with negative images of teenagers, the future, and the world. I have seen the future, and as long as my family is aligned with the Eastside High School student body, I have no fear.

I tell people all the time how amazing these kids are and the amazing love they have for all people with cystinosis. I cannot put into words how deeply I know this. Each year they have chosen CRN, they have risen higher than they believed they could. These events are a competition between schools and their chosen charity. These kids are so much above a silly rivalry between schools; they realize that they are changing the futures for all with cystinosis. This was the first year that Laura really felt the love I have known all along. As the entire student body chanted her name, saying "We love Laura" she broke down in tears. I asked her if she was afraid, and she replied, "No, I just felt overwhelmed".

We love Eastside High School and the students, faculty, and families that make up this community. They love us back. I know I am truly blessed to live in a community that has embraced my family with so much love and support. As the total was announced that Friday night, the kids could care less that they had "lost". The \$106,829 they raised will be matched by the Towsley grant and the NIH fellow will be secured. As the eagle that is their school mascot, they had risen on wings like Eagles...and all of us are soaring with them.

### **Towsley Foundation Awards Matching Grant to CRN**

CRN is pleased to announce that The Harry A. and Margaret D. Towsley Foundation has awarded a matching grant of up to \$150,000 to the Cystinosis Research Network. The grant will be paid over a three year period starting in 2007 and will support CRN's recently established Cystinosis Fellowship at the National Institutes of Health under the supervision of Dr. Bill Gahl.

Many thanks to John Shepperd for securing this funding for one of the most important initiatives CRN has ever undertaken, the recruitment and training of a cystinosis researcher and clinician for the future.



*Students at Eastside High School present an oversized check to Frankie and Laura McGinnis for \$106,829*



*Laura McGinnis and Eastside Student Body President, Kinsey Laurens*

## Eastside High School Raises \$106,829!

### Frankie McGinnis' Journal:

Frankie McGinnis has worked tirelessly in conjunction with Eastside High students to raise money for CRN during Wade Hampton Week. This year, Frankie provided insightful updates to the CRN e-group during the week.

**10/18/07**

*Hi all,*

*Today we kicked off Wade Hampton Week 2007! The students were amazing as always. The students and administrators really encouraged the whole school to get behind us. They want that 100k for the NIH fellowship! There is an article at [goupstate.com](http://goupstate.com) type in McGinnis and it will come up. We are getting some good publicity in this area. They are putting another story in next Tuesday and then the following week about how things turned out. Please continue to send good vibes, prayers, whatever you have as we get ready for this crazy week!*

*Thanks, Frankie*

**10/22/07**

*Hi all,*

*WHW is off to a roaring start. We have been to an assembly, yard sale, car washes, oyster roast, silent auction, McAlister's, jewelry show, and a movie on a tennis court. So far, my best guestimate is that the kids are well over 30k. They are working non-stop. Kinsey, the President, was up from Thursday at 6am until Friday at midnight. Thank God they are young. As usual, it has been amazing. I was sitting in McAlister's eating, and I hear a freshman talking on his cell phone explaining exactly what cystinosis is and trying to get more people to come. That is amazing. Keep the ju ju coming.*

*Much Love, Frankie*

**10/23/07**

*Sad to say but we had the first injury ever and it was a whopper. Yesterday, it was "Polar Bear" slip and slide. We are southerners so 65F counted as Polar Bear weather. Anyway, a 16 year old boy went one direction feet first and another came at him face first. The face lost. He broke his nose and cheek bone. Surgery was today. Other than that things are going real well. We are all walking zombies but having fun. It is 6:30pm, and we have 3 more events sooooo.....off I go again!*

*Much love, Frankie*

**10/24/07**

*Hi all, We continue to have tons of participation from the community and things are going well. I sold suckers at school today and made \$100 in 2 hours!*

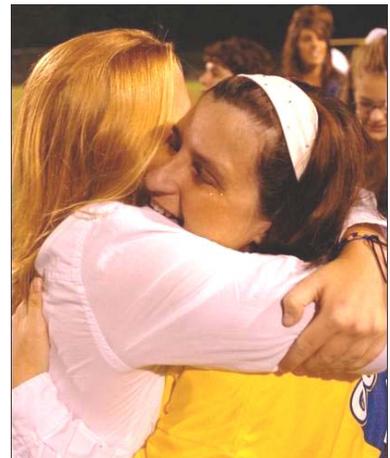
*Love, Frankie*

**10/26/07**

*Hi all, The total was 106,829!!! I am dead.*

*Much love, Frankie*

*Frankie McGinnis receives hugs from Eastside High School Students after they raised \$106,829 for CRN. The money is earmarked for the Cystinosis Fellowship at the National Institutes of Health.*



# Ashley Kazian Wins Miss United States

## Former Eastside High School Student chose Cystinosis as her Platform and is the Cystinosis Research Network Spokesperson

On August 25, 2007, Ashley Kazian was crowned Miss United States in the sixth annual Miss United States pageant. Ashley, age 21, is a junior at the Art Institute of Charlotte. Her dream job is to work as a fashion stylist for Vogue magazine in New York City. In October, CRN named Ashley an official spokesperson. Ashley took some time to answer a few questions about her pageant win and what it means to support cystinosis.

**CRN:** Can you describe the Miss United States organization?

**Ashley:** *The Miss United States Organization is an amazing organization in which the winners will embark on an incredible year of experiences; they will travel throughout the country promoting issues dear to their hearts, they will work with numerous charitable organizations, while meeting various dignitaries and experiencing an unparalleled wealth of personal growth opportunities. These experiences are unique to the Miss United States Organization and will become an integral part in furthering their aspirations. The phases of competition include: Interview 40%, Fashion 20%, Swimsuit 20%, and Evening Gown 20%.*

**CRN:** What made you decide to compete in the Miss United States organization?

**Ashley:** *After working in the pageant industry for over four years for famed designer Gregory Ellenburg, I competed in my first pageant. Ever since I was a little girl, it had always been a dream of mine to be a national titleholder. When I was younger, I would record all of the pageants, and watch them over and over. However, I was uncertain if I would be able to obtain my goal. I started competing in the Spring of 2006. Five pageants, and four crowns later; my dream came true as I was crowned Miss United States 2007.*

**CRN:** How did you choose cystinosis as your platform?

**Ashley:** *I attended Eastside High School, in Taylors, South Carolina where I was on the student government. My junior year our charity during our annual spirit week was The Cystinosis Research Network. I remember calling Frankie McGinnis (mother of Laura McGinnis who has Cystinosis) to ask her a question and we instantly clicked. I began finding reasons to call them or visit, and they have been stuck with me ever since. They are literally my second family. I promised myself that no matter how far I made it in pageants, I would always promote The Cystinosis Research Network any chance I got. The two pageant systems I competed in (United States and USA) do not have "platforms", but I always put that The Cystinosis Research Network was my platform.*

**CRN:** What opportunities have you had to draw attention to cystinosis research?

**Ashley:** *At the national pageant during the interview I was asked about Cystinosis. One question on our fact sheet was: "Who is your role model?" I put that my role model was 11 year-old Laura McGinnis. The judges asked me how someone half my age could be a role model to me. I explained about the disease and what Laura faces on a daily basis, and how she does it all with a smile on her face. I told them that about 5 years ago Laura made me a hand-painted jewelry box and that whenever I come home feeling sorry for myself, the jewelry box catches my eye and puts everything in perspective. It is then that I realize how wonderful I have it, and what Laura struggles with; but how she never complains.*



*Ashley Kazian is crowned Miss United States*

Continued on page 29

## Ashley Kazian Wins Miss United States

*Continued from page 28*

**CRN:** How do people react when you talk to them about cystinosis?

**Ashley:** *It is great to see how interested people become when I explain the disease, and I truly believe that it is all about getting the word out there, so we can get more funding for research. Everyone becomes very interested in the disease and wants to learn more about it. Once they meet Laura, they are automatically hooked and want to do everything they can to help out.*

**CRN:** What plans do you have to promote cystinosis now that you are a spokesperson for CRN?

**Ashley:** *I am truly honored to be chosen as a spokesperson for the Cystinosis Research Network. I plan on using this unique opportunity to promote the disease around the country, wherever I travel. I have brochures that explain what the disease is, and I pass these out when I travel. The Cystinosis website is also printed on my national autograph cards with hopes that people will check out the web. My personal MySpace account talks about the disease, and uses the CRN logo as my wallpaper. I have been in contact with some national news, and talk shows about the disease. I plan on doing everything I can to promote the disease and raise money for research.*

**CRN:** What are your next steps/goals in your pageant career?

**Ashley:** *My pageant career is over after this year, time to hang up my heels ;). I will always be involved in the industry because I love it so much, but I accomplished my goal and I believe after I pass on the Miss United States title, it will be time for me to move on with my life.*

*I am once again honored to be part of CRN and I plan to do anything and everything I can to promote awareness and raise funding for research. If I can assist anyone in fundraisers, please let me know:*

[Amkzn@aol.com](mailto:Amkzn@aol.com)

[www.MissUnitedStates.net](http://www.MissUnitedStates.net)

864-346-6539



Laura McGinnis and Ashley Kazian



*Ashley Kazian postponed a modeling job in California to stay in South Carolina and support Wade Hampton Week at Eastside High School*

## Stilke's PartyLite Fundraiser Raises \$380

Kirsten and Dave Stilke hosted a PartyLite candle party on April 15 to raise money for the Cystinosis Research Network. About 30 guests arrived for a candle demonstration and to learn more about cystinosis. The Stilke's have two children with cystinosis, Mason and Livia.

Kirsten spoke to the group to educate them about cystinosis. She emphasized the importance of supporting the Cystinosis Research Network in its search for a cure. Kirsten received a positive response, and a few tears were shed as she addressed questions about her kids that friends and family were always afraid to ask.

Kirsten had brochures made with pictures of Mason and Livia on them. Each guest took 4-5 brochures and vowed to spread the word about cystinosis. When the orders came in, Kirsten made postcards for each guest thanking them for their donation.



*Livia and Mason Stilke*

The party raised \$380 for the Cystinosis Research Network and tons of awareness! Kirsten and Dave hope to have another fundraiser next year.

## Usborne Book Fundraiser Raises \$105

Hi all,

I just wanted to introduce our daughter Carleigh Rose DeCroce to the Cystinosis family. Carleigh was diagnosed last October at the age of 2. She is now celebrating her 3<sup>rd</sup> birthday and doing so much better today. This would not be possible without the Cystinosis Research Network and all the families striving to find a cure.

In order to show our appreciation and to help fund the Cystinosis Research Network, we held an online fundraiser. As an Educational Consultant for Usborne Books, during the month of October (in honor of Carleigh's birthday), I donated \$1.00 for each book purchased online at [www.ReadMeAnother.com](http://www.ReadMeAnother.com). We raised \$105, and some people are making donations directly to CRN. I look forward to continuing this fundraiser year after year. Everything great starts with the first step!

Regards,

Joan DeCroce (mom to Anthony 8 w/o and Carleigh Rose 3 w)



*Carleigh DeCroce*

## 5K Fun Run/Walk Raises \$11,000+ for CRN

A 5K Fun Run/Walk was held in Bloomfield Hills, Michigan on April 29, 2007. All proceeds from the event were donated to the Cystinosis Research Network in honor of Kacy Wyman. The event was organized by three seventh grade boys who are friends of Kacy's oldest brother, Matt. They made flyers and held the event for their community charity project. The boys hoped to raise \$1,000 for the CRN and raised \$11,300!

The weather was gorgeous, and over 200 community members showed up to support cystinosis research. The Wymans are so proud and thankful! CRN would like to extend a special thanks to Jarred Bratley, Zack Neff, and Jacob Ruby, the remarkable boys who organized the fundraiser!

## The Reed Family Raises \$500 for CRN

Inspired by the CRN Family Conference, the Reed Family hosted a fundraiser for the Cystinosis Research Network during the Oldham County Roundup in Vega, TX. Deb and Max Reed, grandparents of Mason Reed, made balloons with the CRN logo and accepted donations in exchange for a balloon.

Kylene and Ryan Reed made wooden crosses that were raffled. Ryan Reed's brother, Gary and wife, Megen, helped with the fundraiser as well. Mason rode is four wheeler in the Roundup parade and pulled brother Jaxon behind him! In all, over \$500 was raised for CRN!



*Mason Reed made signs for his four-wheeler to ride in the Roundup Parade with brother Jackson.*



*Mason Reed hands out balloons with the CRN logo in exchange for a donation.*

## The Wysocki Boys Donate Birthday Money

Lucas and Shane Wysocki celebrated their birthdays on June 16, 2007 with a firetruck-themed party and generous guests! Lucas turned three, and Shane turned one. The Wysocki family asked that their guests donate to the Cystinosis Research Network in lieu of birthday gifts. Lucas and Shane's friend, Jacob Ellerbrock, age 2 1/2, has cystinosis. In the words of Lucas Wysocki, they want to help their friend "get better."

Lucas and Shane raised \$1615.00 for CRN! Lucas and Shane's mom and dad, Kelly and Mike, feel that they not only raised money but also awareness for cystinosis. Kelly said the party was one of the best experiences she has had.

"The Ellerbock's mean A LOT to us," Kelly said, " and we want nothing more than for an eventual cure for cystinosis."



*Jacob Ellerbrock*



*Mike, Shane, Kelly, and Lucas, Wysocki*



*Jacob Ellerbrock with his Mom, Mary, and Dad, JJ*



*Jacob Ellerbrock at the Wysocki's fire truck-themed birthday party*

## C.H. Robinson Golf Tournament for Cystinosis

By Tim Miller and Pam Woodward

On Sept. 8, about 25 C.H. Robinson employees from CHRW-Salt Lake City, Southwest Produce Division, Savannah, Los Angeles International branches, and National Accounts along with Mijken Cassidy from Kofford Trucking, Scott Tucker from Rocky Mt Music, Rory Boyer, Frankie and Laura McGinnis, and Rock, Pam and Tahnie Woodward golfed or volunteered for a charity golf event. It was held at the beautiful Johnny Miller signature course at Thanksgiving Point located in Lehi, Utah. They raised over \$27,000, all of which will go to The Cystinosis Research Network.



*Laura McGinnis and Tahnie Woodward*

Why Cystinosis research? Manager Tim Miller of the Salt Lake City Branch explains. "Last year the office held a golf outing that was free to our customers. We had about 90 customers show up, and it was a great time. At the end of that event, I felt that the branch should find a charity to support and raise some money. So we did some research, had the employees submit nominations, and held a meeting to review the top three charities. One of the charities was Cystinosis. Liz Swenson from the Salt Lake City branch has worked with Kofford Trucking for many years and is friends with Pam (Kofford) Woodward from Kofford Trucking. Pam's daughter Tahnie has Cystinosis."

"While we considered larger or more popular charities, the office felt the money we would raise for Cystinosis would go a long way towards helping the 2,000 children and young adults with the genetic disorder. Because there are so few people with Cystinosis, it is considered an "orphan disease" and pharmaceutical companies don't do research or develop medicines for the disease. The Cystinosis Research Network has doctors that are researching for them. All money raised goes directly to the Charity as it is a non-profit organization and all board members are volunteers, who have a child, grandchild or Cystinosis themselves."

A total of 146 golfers participated, including customers. The winning foursome from Tread Systems, which shares the same building as the Salt Lake City branch, received 4 tickets each to a Utah Jazz game of their choice and \$100 gift certificates to the Thanksgiving Point Pro Shop. Second place winners, which included Scott Tucker from Rocky Mt Music each received one foursome to the Thanksgiving Point Golf Course and \$50 in gift certificates. Third place won C.H. Robinson duffle bags filled with shirts, hats, sweat-shirts, a pocket knife, sunglasses, and more.

There was also a raffle which included numerous prizes donated by customers, local merchants and Cystinosis families. So there were lots of winners besides just those that golfed well.

Tim Miller reflected, "As I drove home after the event and added in my head what I thought we had collected in entry fees, donations and sales of Mulligan's, Red Vine licorice, Pay the Pro, Better you Ball, and Your Final Resting Place fees, I could not stop smiling. I had to call Pam and let her



*Pam and Rock Woodward with Laura McGinnis*

*Continued on page 34*

## C.H. Robinson Golf Tournament for Cystinosis

*Continued from page 33*

know that I figured we had made about \$27,000 for the charity. She was speechless. She had figured we'd make about \$5000. When I got home I kissed the wife and told her, 'We did a good thing today.'

Pam would like to thank **all** of the C.H. Robinson employees who volunteered their time for the golf tournament. Tim Miller the Utah branch manager and especially Alicia Martinez-Madsen and Liz Swenson who worked countless hours getting all the donations and the golfers lined up. C.H. Robinson plans on doing it all over again next year. So all you golfers mark your calendars and come to Utah on **September 6, 2008**.



*Pam and Tahnne Woodward with Frankie and Laura McGinnis*

## Ricardo, Inc. Raises \$500 for CRN

On March 30, 2007, employees at Ricardo, Inc. donated money to cystinosis in exchange for wearing jeans to work. The company raised \$500 for the Cystinosis Research Network in honor of Steve Schleuder, age 18, with cystinosis.

Steve's dad, Carl, works for Ricardo, Inc. The company selects organizations to be the beneficiaries of charitable events based on requests from employees. Carl requested a "Jeans for a Cause" event in honor of Steve. Carl wrote a flier about Steve and cystinosis and included a photo. The flier was posted throughout Ricardo, Inc.

Ricardo is the premium global deep-content engineering and management consulting partner for automotive, commercial vehicle and related industry sectors. The company provides complete engineering services from strategy through product concept, design release and validation, and all phases of the product lifecycle. Its headquarters are in Belleville, Michigan.

The company has been supporting various charitable organizations for a little over a year. It all started with the Jeans for a Cause, Breast Cancer awareness, and has continued with heart felt donations from the employees. The fundraising efforts are a collaborative effort between all U.S. Ricardo, Inc. offices on a monthly basis. On average, they send about \$300 to each organization they support.

During the months of November and December, they take a break from "Jeans for a Cause" and "adopt" a child for the holidays.

## Fourth Annual Jack's Family Fun Day

**By Christy Greeley**

The fourth annual Family Fun Day in honor of Jack Greeley to benefit the Cystinosis Research Network was held on August 26, 2007 in Lincolnshire, Illinois. The event was a great success, with perfect weather and several hundred people in attendance. Tamarak Country Day School and Camp again graciously hosted the event, providing the perfect venue and generous support in many ways.

This year's attendees enjoyed an expanded raffle and silent auction, games, pony rides, food, s'mores sponsored by the local Y-Guides, a bake sale sponsored by Jack's Cub Scout den, arts and crafts, a balloonist, dancing, face painting, bounce house, football toss, swimming, basketball, and much more. Nearly 70 sponsors donated items and services for the event, which contributed to this year's proceeds of almost \$17,000. Family Fun Day has raised nearly \$57,000 for CRN over the past four years.

Our family cannot thank those enough who have made this amazing community event so successful. From our friends Jodi Kirsh and Dawn Weiland for coming up with the initial idea, to Kathy Gordon for spending so much time and energy expanding on and running the event the past two years, to all of our wonderful friends for volunteering to help, to Dave and Lucia Thoensen, the owners of Tamarak for so generously donating their beautiful grounds each year. We are so blessed to have the support of our friends and family, Family Fun Day could not have happened without all of you!



*Jake Shapiro, Robby Weiland,  
and Jack Greeley*



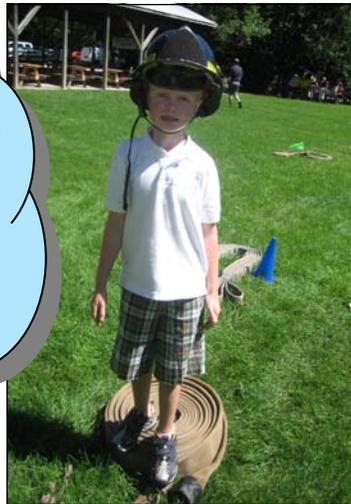
*Jack Greeley picks the winning names*



*Alex Greeley with Evan LeBeau*

# Fourth Annual Jack's Family Fun Day

A hero cannot be a hero unless in a heroic world.—  
Nathaniel Hawthorne



*The Greeley Family received the following letter from a high school student whom they had never met after Family Fun Day was featured in their local newspaper.*

Dear Greeley Family,

My name is Jeff Baker, and I am a junior at Stevenson High School. I recently had a garage sale with my family and collected a small amount of money. My family and I stumbled upon your article in the newspaper. It was heartbreaking to hear about a child that has to live with the disease of cystinosis. I envy him for having enough courage to fight this and live his life as any other child would. I also am amazed at how many doses of medicine Jack has to take a day, but thankful there is such a medicine. We decided as a family to donate our earnings to your family. It is clear that it will be much more useful in your hands. We hope what little we could donate will help in researching a cure for this disease.

Sincerely,

Jeff Baker



## Second Annual Carnival for a Cure

By **Brittney LeBeau**

On Oct. 12<sup>th</sup>, the 2<sup>nd</sup> annual Carnival for a Cure was held at Community Christian Church in Naperville Illinois honoring Alexis and Evan LeBeau. Seventy-six families attended and \$16,000.00 was raised for CRN.

Families and their children enjoyed pumpkin painting, carnival games, fire truck slide, face painting, moon jump, book sale, bake sale, and 65 silent auction items. A new addition was added, an adults only Corn Toss (Baggo) Tournament, which came down to an exciting finals. The highlight of the night was a live bid-off emceed by Rudy Stefanski for a custom built birch cubby storage unit. The bidders, Tammy Bruner and April Levosky went back and fourth until the last bid was up to \$875.00. With a new bid in the waiting Dave Hulthen of Hulthen Woodworking offered to make another unit, so we sold two units for a total of \$1,750.00!!

We personally want to express our heartfelt gratitude to all those who attended, made the silent auction donations, all of our sponsors (Lainey Lang of Baird & Warner, the Naperville Baird & Warner office, and Gorton's Fish), and all those who donated their hard work and time to volunteer in making this Carnival such a great success! Finally none of this would have happened without the hard work and long hours put in by Amber Stefanski. We would like to sincerely thank Amber for putting together another successful Carnival for a Cure to help find a cure for Cystinosis!



*Alexis LeBeau and her friend, Emily*



*Amber Stefanski stands in front of the pumpkin painting area. Amber coordinated "Carnival for a Cure"*



*CRN displays educated attendees about cystinosis. Brittney LeBeau added Alexis and Evan's daily schedules to the display*

## Second Annual Carnival for a Cure



*Rudy Stefanski emceed the bid-off while Tammy Bruner and April Levosky try to outlast each other*



*The adult Bagger tournament was a hit!*



*Courageous volunteers helped with pumpkin painting*



*The painted pumpkins!*

### Make an Online Donation through Network for Good!



Did you know that you can make a secure online credit card donation to the Cystinosis Research Network through Network for Good?

- You can dedicate a donation to someone specific. Network for Good passes along your dedication to CRN
- You will receive a record of your contribution for tax purposes.
- Great way to give for the holidays!
- Go to <http://www.cystinosis.org/help.html> for more information

## Leombruniville Raises \$2200+ for CRN

**By Paula Shal**

*Question:* What do you get when you combine a tropical atmosphere, five cardboard swimsuit models, and a room full of generous people?

*Answer:* The Leombruniville “Bartending for Charity” fundraising event for the Cystinosis Research Network!

Leombruniville took place on May 19, 2007 at Leombruni’s Italian Village in Byron, Illinois. The event was held in honor of Paula Shal, age 36, and all individuals with cystinosis.

Paula's sister and brother-in-law, Deb and Jim Eisfeller, coordinated the event, and Ernie and Mimi Leombruni generously donated their facility and provided appetizers.

The event was publicized in local newspapers and at Leombruni’s. Invitations were sent through the mail and e-mail. The bottom of the invitation included a form to send a donation for those who could not attend.

Deb, Jim, and family friend, Ralph Larson served drinks all night. Tip buckets were set up on the bar, and all their tips were donated to CRN.

Live music was provided by singer/songwriter LoJo Russo ([www.lojorusso.com](http://www.lojorusso.com)). A silent auction, live auction, and 50/50 raffle also took place throughout the night with Jim Eisfeller multi-tasking as the “bartending auctioneer.” Auction items were donated by family, friends, and local businesses. Some items included a weekend cabin getaway, a beauty and tanning package, a photo package, autographed Dick Vitale items, an American Girl doll, and more! The Leombrunis donated bar signs, a wine basket, the cardboard models, and even the NASCAR tip buckets were auctioned off at the end of the night!

Dan Powless won the 50/50 raffle and donated his winnings back to CRN! In all, the fundraiser raised over \$2,200 for CRN! Company matches matched some of the earnings, and \$200 was earmarked for the Sierra Woodward Scholarship fund in honor of Paula Shal’s siblings.

A special thanks goes out to Deb and Jim Eisfeller, Ernie and Mimi Leombruni, Ralph Larson, Darcie and Mike Feltmeyer (Paula’s sister and brother-in-law), Logan Feltmeyer (Paula’s niece), and Jan and Jerry Frye (Paula’s mom and dad).



*Ralph Larson, Deb Eisfeller, and Jim Eisfeller pose with a cardboard swimsuit model at Leombruniville*

# Leombruniville Raises \$2200+ for CRN



*Dave Greeley, Christy Greeley, and Paula Shal*



*Paula Shal's parents, Jan and Jerry Frye*



*Jim and Paula Shal*



*Singer/Songwriter LoJo Russo and Paula Shal*



*Jordan Feltmeyer, Amanda Swinda, Caleb Feltmeyer, and Mike Feltmeyer*

## 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

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.

## Take Action!

CRN strives to inform the Cystinosis Community of current issues that may impact individuals with cystinosis. Since transplantation affects many individuals with cystinosis and their families, we have included some current legislation on transplant issues.

### **Help Extend Medicare Coverage for Immunosuppressive Drugs**

People who have had organ transplants must take immunosuppressive drugs for the life of the transplant in order to reduce the likelihood of the organ being rejected by the body. Currently, Medicare pays for most transplants and covers drugs for 36 months after the transplant even if the person does not qualify for Medicare because of age or disability status. At the end of this time, the kidney recipient must pay for immunosuppressive drugs through private insurance, pharmaceutical programs, or pay out-of-pocket.

Too often, kidney patients must choose between taking the medication they need or other living expenses, and they cut doses or stop taking the medication, causing the transplant to fail. Some dialysis patients don't even consider a transplant because they know they will not be able to pay for the drugs.

Although immunosuppressive drugs are very expensive, costing \$10,000-20,000 per year, if the kidney transplant fails, the person returns to dialysis at a cost of over \$65,000 per year to Medicare. In addition, there are over 75,000 people on the waiting list for kidney transplant, and it is poor stewardship to lose a kidney because the patient can't afford the necessary drugs to keep it working.

Congressmen Dave Camp (R-MI) and Ron Kind (D-WI) have introduced H.R. 3282 that would extend Medicare for immunosuppressive drugs for the life of a kidney transplant. Patients would continue to receive these drugs under Part B of Medicare with the usual premium but would not have access to other Medicare services or coverage. This is a big step forward to preserve the life of kidney transplants.

Please write your Representative today and ask them to co-sponsor HR 3282. Share your story, or the story of a loved one, about the importance of immunosuppressive drug coverage.

### **Kidney Care Quality and Education Act**

Over 335,000 Americans have 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 to improve the well-being of dialysis patients. Send a message to Congress now!

Kidney Care Quality and Education Act (S. 691) would:

- Establish a Medicare education program for patients before they reach kidney failure to empower them to plan ahead and make the best choice 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 the barriers to home dialysis therapy and how to remove those barriers.
- Create a national training standard for dialysis technicians to ensure quality care.

The House of Representatives included many of these provisions in their recent Medicare reform legislation that passed in August. Now the Senate is considering what will be included in its Medicare reform legislation. By co-sponsoring this legislation, we can show there is support for these provisions in the larger Medicare bill.

Please act now and ask your Senators to support this important legislation!

**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 March 1, 2007 and October 31, 2007.

### Leadership Circle (\$5,000-\$25,000)

Sigma Tau Pharmaceuticals  
Safeway Foundation in honor of Alexis & Evan LeBeau  
Cause 2 Celebrate bowling fundraiser in honor of Kacy Wyman  
H.E.B  
Amy Stieren in honor of John Ben and Ava Shepperd  
C.H. Robinson Co. golf tournament in honor of Tahnje Woodward  
Timothy Miller for the C.H. Robinson golf tournament in honor of Tahnje Woodward

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

Alyssa Horrigan in honor of Jack Greeley 7<sup>th</sup> Birthday  
James & Lisa Dvorak in honor of Jack Greeley's Family Fun Day  
Raymond James Global Account in honor of Kacy Wyman from Ronald Gunther  
Scott Tyler of Tyler, Dumas, Reyes for Garden Gala in honor of Kacy Wyman  
Jose and Velyna Morales through United Way of New York City in honor of Christian Morales  
Ms Sharon Jester Turney through United Way of New York City in honor of Christian Morales  
Brandy and Jeremy Stanford & Friends Golf Tournament in honor of Neveah Stanford  
Joseph A. DeNucci golf tournament in honor of Shea Hammond  
C.H. Robinson Co. golf tournament in honor of Tahnje Woodward

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

Shad Reed-Dalhart High School Basketball team-Pancake supper fundraiser in honor of Mason Reed  
Mastec  
Lefkosky Family Foundation in honor of Kacy Wyman Fun Run/Walk  
David & Kathryn Petoskey for the Garden Gala in honor of Kacy Wyman  
Jeffrey & Kathleen Abrash for the Garden Gala in honor of Kacy Wyman

William Blazo for the Garden Gala in honor of Kacy Wyman  
Chris & Tracie Shepard in honor of Jack Greeley's 7<sup>th</sup> birthday  
Towsley Foundation  
Shirley Schindler  
Mary & Alfred Shepperd in honor of John Ben and Ava Shepperd  
Alfred Shepperd in honor of John Ben and Ava Shepperd  
John Ben Shepperd Estate in honor of John, Kim, Ben and Ava Shepperd  
Lawrence & Shirley Manning in honor of Megan Morrill and Dr. and Mrs. Stephen Doezema  
Leombrunville Fundraiser in honor of Paula Shal  
Michelle & John Kelly for the Garden Gala in honor of Kacy Wyman  
Ms Sharon Jester Turney through the United Way of New York City in honor of Christian Morales  
Sigma Tau Pharmaceuticals for Education Grant (NORD)  
Baxter International Foundation Matching gift from Michael Shapiro in honor of Jack Greeley's Family Fun day  
Peter Nick in honor Jack Greeley's Family Fun day  
Tammy & Jeff Bruner for Carnival for a Cure in honor of Alexis & Evan LeBeau

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

Mark & Denice Flerchinger in honor of Tina Flerchinger  
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Jose and Velyna Morales through United Way of New York City in honor of Christian Morales  
J. Martinez III in honor John Ben and Ava Shepperd  
Doris Muller in honor of Jancie Finn  
Ernest Sacco in honor of Shea Hammond

Phil & Judy Stilke in honor of Livia and Mason Stilke  
David & Kristin Sliwicki in honor of Jack Greeley's Family Fun Day  
April Levosky for Carnival for a Cure in honor of Alexis & Evan LeBeau  
Michael Mattson for Carnival for a Cure in honor of Alexis & Evan LeBeau  
Karl Heergededen-Northstar Group, Inc in honor of Jack Greeley's 7<sup>th</sup> birthday  
Jean Hooper-Attwater Blue Corp. in honor of Jack Greeley's 7<sup>th</sup> birthday

### *For the Garden Gala in honor of Kacy Wyman:*

Scott & Tia Carmichael  
Deborah & David Gillespie  
Nancy Haddad  
Susan Howard Irwin Groskind-Northern Lakes Seafood & Meat  
Keith Kallen  
Daniel McAleer

### *For Miracles at Milleridge Fundraiser in honor of Laura Krummenacker:*

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Patricia Glueckert  
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Melodie Volante

### *For the C.H. Robinson golf tournament in honor of Tahnje Woodward:*

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Scott & Joni Satterlee  
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## Gifts and Donations

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Tyco matching gift of Chuck Davis in honor of Shea Hammond  
 Tyco matching gift of Chuck Davis in honor of Shea Hammond  
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 Elaine Darbee for the cystinosis fun run/walk in honor of Kacy Wyman  
 Brian & Cari Dawood for the cystinosis fun run/walk in honor of Kacy Wyman  
 George Stieren in honor of John Ben & Ava Shepperd  
 Gloria Kane in memorial to Annie Gunsauillus  
 State of Washington 1<sup>st</sup> Qtr CFD donations  
 Sally & Messner in honor of Kellen Binger  
 State of Washington 2nd Qtr CFD donations  
 Richard Gimenez in honor of Shea Hammond  
 Jamison Group Inc. in honor of Kacy Wyman  
 Travelers Community Action Awards from Nancy Finn & Maureen Skei  
 Dana Drury for Carnival for a Cure in honor of Alexis & Evan LeBeau  
 Dr. Susan Thomas Schendel & Mr. James Thomas for Dr. Corinne Antignac's in vivo cystinosis gene transfer project

#### *For Jack Greeley's 7th Birthday:*

Dana Dressler  
 Terry Hagy of RentalMax L.L.C.  
 Chris & Deb Kiah  
 William & Roxanne Schneider

#### *For the Garden Gala in honor of Kacy Wyman:*

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 Shari & Eric Dobrusin  
 Nancy & Gerald Finn  
 Michael & Ellen Grimes  
 David & Lori Horton  
 Long Beach Republican City Committee  
 Debra & Neil MacDonald  
 Andrew & Catherine Paulson  
 Mike Sanford of Varsity Lincoln  
 Jennifer & Tim Wyman

#### *For the Miracles at Milleridge fundraiser in honor of Laura Krummenacker:*

Joseph Carrello  
 Maryellin Cordaro  
 William Cox  
 Angelo Mianulli  
 Deborah Murphy  
 Edward Olsson  
 Nancy Rooney

#### *For Jack Greeley's Family Fun Day in honor of Jack Greeley:*

James Dvorak  
 Marcia Elkin  
 Lincolnshire Animal Hospital  
 Leslie McDonnell  
 Michael & Julie Muth  
 Patrick & Laura Sack

#### *For the C.H. Robinson golf tournament in honor of Tahnne Woodward:*

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Witmeyer & Allen, PLC in honor of Alex Weaver 10 K  
 John McGarvey in honor of Alex Weaver 10 K  
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 Gayle & Darrin Elias Previn Mankodi in honor of Samantha Jane Circello  
 Clinton & Linda Tarpley in honor of Paula Shal for the Leombrunville Fundraiser  
 Tony & Ruth Ann Ahnen in honor of Katie Ahnen  
 Betty Berry in honor of Michael Covington

## Gifts and Donations

Kristina Lewis in honor of Holt Grier  
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 Elizabeth Broadway in memory of Annie Gunsaulus  
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 Daniel Ricards in honor of Tahnier Woodward  
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 Leona Sheffield in honor of Mitchell Smith  
 John Luxton in honor of Alex Weaver 10 K  
 Bloomfield Hills Middle School in honor of Kacy Wyman for cancellation of fun night  
 United Way of Greenville County  
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 Terry & Tara Savarise  
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 Peter & Dolores Nick  
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*For the Garden Gala in honor of Kacy Wyman:*

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*For Carnival for a Cure in honor of Alexis and Evan LeBeau*

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 Brian Theis  
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Milleridge fundraiser in honor of  
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Thomas Lyons  
John Pease  
Thomas Hackett

*For the Miracles at  
Milleridge fundraiser in honor of  
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Jacquelyn Frey  
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Debra Dowdell  
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*For the Cystinosis Fun Run/Walk in  
honor of Kacy Wyman:*

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Alan & Leslie Ruby  
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*For the C.H. Robinson golf tournament  
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Kay & Susan Swenson  
Michele Horsley  
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## Gifts and Donations

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 Cindy Collins in memory of Roy Nance  
 Lonnie Riddle in memory of Roy Nance  
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 Mason & Livia Stilke  
 Wallace & Wallace Realtors in memory  
 of Roy Nance  
 Richard & Cindy Krzywy in honor of Ma-  
 son & Livia Stilke  
 Beverly Shull in memory of Annie  
 Gunsaulus  
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 Douglas & Betsy Floski in honor of  
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 Livia & Mason Stilke  
 Marilyn & William Moll in honor of John  
 Ben and Ava Shepperd for conference  
 Phyllis Tondelli in memory of Annie  
 Gunsaulus  
 Cynthia Brunson in honor of Mason &  
 Livia Stilke  
 Candace Wickstrom in honor of Tahnje  
 Woodward for her fundraiser  
 Catherine Keppers in honor of Kacy  
 Wyman  
 Diane Sancer in honor of Holt Grier  
 Tim & Joyce Marker in honor Kacy  
 Wyman mom's Elaine bday  
 William Stallworth MD in memory of Roy  
 Nance  
 Kathy Waldrip in honor of Mason Reed  
 for Rise to the Occasion, Balloons on  
 the Square fund.  
 Max Reed Farmin honor of Mason Reed  
 for Rise to the Occasion, Balloons on  
 the Square fund.

### *For Carnival for a Cure in honor of Alexis and Evan LeBeau:*

Brian & Erin Smith  
 Ronald & Kandace Gasperini  
 Nate & Jean Miller  
 Antonia Parrish  
 Kristen Wydra  
 Rebekah West  
 Linda Sterling  
 Dante & Patricia Janes  
 Mary Beth Klaas  
 Sharon Hylek  
 James Angel Leciejewski  
 John VanDerVoom

### *For the Garden Gala in honor of Kacy Wyman:*

First United Methodist Church  
 Dana Davis  
 Ronald & Sandra Baker  
 Cranson Jones Garden Gala  
 Thomas Wyman Garden Gala  
 Kost Elisevich Garden Gala

### *For the 10K in honor of Alex Weaver:*

Chucker & Reibach Attorney's & Coun-  
 selors at Law  
 Craig Cooley  
 Ramon Chalkley  
 Loretta Ross  
 John Lafrattain  
 Beverley & James Curry  
 Richard Fuller  
 Kristin Mavromatis

### *For the C.H. Robinson golf tournament in honor of Tahnje Woodward:*

Stan & Karen Saltas  
 Ryan & Michelle Heinhold  
 Gary Brockbank  
 Landon Potter  
 Michelle Horsley

### *For the Wysocki Boys' Birthdays in honor of Jacob Ellerbrock:*

Hans & Carolyn Andrews  
 Paul & Kirsten Cwinski  
 Julie Vanburen  
 Laura & David Anderson

### *For Jack Greeley's Family Fun Day in honor of Jack Greeley:*

Michael & Jennifer Bott  
 Kathleen Jones  
 William & Jennifer Axelsen  
 David Fossier  
 Allen & Jodi Kirsh  
 Julie & David Spokane  
 John & Elizabeth Imus  
 David & Joy Holecek  
 Anne & Timothy Ryan  
 Montgomery & Colleen Cornell  
 Rob & Ingrid Michael  
 James & Tiina Arcara  
 Gerard & Colleen Leider  
 Cameron & Nicole Colvig  
 Rob & Ingrid Michael  
 James & Tiina Arcara  
 Christopher & Christine Baker  
 Phil & Diane Lefebvre  
 Paul & Laura Russo  
 Gary & Kathy Gordon  
 Diane Gillis  
 Christy & Dave Greeley  
 Karen Bloodgood  
 Catherine & Gregory Woodward  
 Jennifer & James Sturgeon

### *For Jack Greeley's 7th Birthday:*

David & Carolyn Griffith  
 Roxie Weber  
 George & Marjorie Tattersfield  
 Theresa Spath  
 Lorraine Argo  
 Maarten and Anne Van Gerven  
 Bob Laskowski  
 Michael DaynesFeld Entertainment, Inc  
 Char Catt-Lyon Catt Lyon Design  
 Greg Carney Denver Broncos  
 Aaron & Suzanne Siegel  
 Carl Bassewitz The Bassewitz Group

## Gifts and Donations

*For the Miracles at  
Milleridge fundraiser in honor of  
Laura Kruppenacker:*

Quality A/C & Heating Inc  
RB Irrigation LLC  
MJR Management  
William Fore CPA PLLC  
Bills Towing Service Inc  
Flowers by Peter of Hicksville  
William Zounek  
Edward Hebron  
Harold Mangarelli  
Anthony Agosto  
Linda Biagini  
Susan Ragusa  
Arthur Beechert  
W Koenig  
Ralph & Marilyn Pagano  
Burton & Sandra Watson  
Lawrence Misita  
Bernard Finn  
Florence Melody  
Michael & Melanie Mandell  
Patty Golder NBC 5  
Andrew Hill  
Lawrence Kruppenacker  
Regina Phillips  
Megan Asher  
Allyson Costas  
Elizabeth Fetta  
Christopher Fetta  
Donald Glueckert  
Irene Kassimis  
Eleanor Forte  
Dorothy Murphy  
John Urbielewicz  
Kurt Ludwig  
Carol Fiorenza  
Doris McDermott  
Geraldine Pettas  
Lisa Whelehan  
Maryanne Dealy  
Rob Darienzo  
Terry Wulforst  
Joseph Palermo

*For the Cystinosis Fun Run/Walk in  
honor of Kacy Wyman:*

Jeffrey Burmeister  
Lori Kontry  
Barry M. Feldman, Attorney at Law  
Urban Blues  
Metal Design & Manufacturing, LLC  
Dean & Gay Cuddy  
Mitchell & Norma Shek  
Edward & Amy Rychlick  
John & Michelle Kelly  
George & Patricia George  
Joseph & Gina O'Mara  
Howard & Beth Neff  
Andrew & Linda Markowitz  
Judith & William Gray  
Matthew Chope  
Grant & Melissa Williams  
Julie & William Stern  
Carolyn & Christopher King  
Melissa & Richard Small  
Gregory & Ann Seraydarian  
Lisa Epstein  
Thomas & Lisa MacKillop  
Ruth Pomish  
Roberta & Paul Bresette  
Robert & Ilene Darbee  
Sheldon Olson  
Matthew Chope  
Dennis & Vicky Winkler  
Steven & Melanie Lefkofsky  
Douglas & Marlene Eng  
Roger & Barbara Trunsky  
Stacey Olson  
William & Julie Maher  
Craig Singer  
Thomas & Molly Saeli  
Tim & Jen Wyman  
Kathleen DuHame  
Hamid & Deborah Banooni  
Rochelle Lederman Trste  
Shauna & Richard Elias  
David & Lori Horton  
Seelye Equip. Specialists  
Mark & Terri Morawski  
Dawn Asadoorian  
Samuel & Lori Gray  
Loren Stone  
Barbara Cooney  
Jeffrey Burmeister  
Michael & Suzann Neff  
Jeffrey Burmeister

### **Friends (up to \$49)**

Jeane Gilter in honor of Mason Reed for Rise to the Occasion, Balloons on the Square fund.  
Jeanne Zautner in honor of Mason & Livia Stilke  
Kim & Scott Johns in honor of Mason & Livia Stilke  
Llan Benhanan  
Velgene & Cynthia Karstens in honor of Michael Covington  
Billy & Lorraine Stonesifer in memory of Roy Nance  
Gene Johnson in honor of Mason & Livia Stilke  
John & Sharon Keilty in honor of Margaret Halloran & in memory of Sandra Nickerson  
Daniel & Jean Zautner in honor of Mason & Livia Stilke  
Donna Circello in honor of Samantha Jane Circello  
United Way of Jefferson & N. Walworth Counties donation from B Johnson 2006  
Oma Benson in memory of Roy Nance  
Daniel & Jean Zautner in honor of Mason & Livia Stilke  
Donna & Andy Wojdula in honor of Mason & Livia Stilke  
Steve & Padget Flowers in honor of Mason & Livia Stilke  
Bob & Nicky Brigke in honor of Mason & Livia Stilke  
Arlene Palmgren in honor of Mason & Livia Stilke  
Lawrence & Pearl Chernow in honor of Mason & Livia Stilke  
Royal Garden's Social Assoc  
David & Pamela Witherell in honor of Russ Halloran 70th bday  
Becky Gross in honor of Jean Zautner  
Sarah Lemessurier in honor of John Ben and Ava Shepperd for conference  
Caryl McCaulouin honor of Mason & Livia Stilke  
Kathleen Barlow in memory of Annie Gunsaulus  
Jessica King in honor of Samantha Jane Circello  
Wayne or Marian Vermeline in honor of Michael Covington

## Gifts and Donations

Violeta Murgado-Lombardia in memory of Annie Gunsaulus  
 Cynthia Ratner in honor of grandson, Holt  
 Nancy Davis in memory of Sandra Willis Orange County United Way  
 Thomas & Carol Sheahen in honor of Mason & Livia Stilke  
 Rock & Pam Woodward in memory of Clarise Richards  
 Gary & Kathy Shaw  
 Donald & Shirley Richardson in honor of Mason Reed for Rise to the Occasion, Balloons on the Square fund.  
 Jaylene Parsley in honor of Mason Reed for Rise to the Occasion, Balloons on the Square fund.

*For the 10K in honor of Alex Weaver:*

Clara Cheney  
 Carl & Brenda Johnson  
 James & Belinda Brown  
 Michael & Gail Jackson  
 Kay Frye  
 Michelle Dawson  
 Janet Brown  
 Brian & Julie Goolsby  
 Gary & Sonia Hicks  
 Catherine & Paul Hammond  
 Patricia & Gerald McCarthy  
 Cheryl Frydrychowski  
 Esther Windmueller  
 Debra & Mark Nedervelt

*For the Miracles at Milleridge fundraiser in honor of Laura Kruppenacker:*

Alexander Chebuske  
 Werberman Assoc  
 Nancy Finn  
 Diane Sullivan  
 Patricia Collier  
 Laura Matthiessen  
 John Visceglie  
 Steve Kelly  
 Rose Rufrano  
 Frances Simile  
 Teresa Granados  
 Lionel McMahon  
 Patricia Musynske

*For Jack Greeley's Family Fun Day in honor of Jack Greeley:*

David & Sandra Coyner  
 Jeff & Karen Steybe  
 Daniel & Pamela Loewenstein  
 Jeffrey & Karen Burnham  
 Jeffrey & Angela Depew  
 Joseph & Antoinette Talanges  
 James & Monica Fairman  
 Debra Hom  
 Diane Gillis  
 Christy & Dave Greeley  
 Joseph & Gail Saliba  
 Lesa Vidovic  
 Dwight & Robin Ekenberg  
 Harriet or Barry Goldberg  
 Jacqueline & Christopher Curtis  
 Bradley & Marlene Saks  
 David & Kristin Keevins  
 Peter & Dolores Nick  
 Cassandra & Ed Horvath  
 Alan & Lisa Jagiello  
 Garrin & Julie Kapecki  
 Todd & Robin Naughton  
 Joshua & Lisa Gordon  
 Michael & Amy Gordon  
 Matthew & Rebecca Rendl  
 Bernard & Roberta Coniglio  
 James & Nancy Thoma  
 David Fossier  
 Jeff Greenbury  
 Douglas & Kelly Dupont  
 Debra Ponce De Leon  
 Ivan & Kathleen Knezevic  
 Sandra & Douglas Simon  
 Dr. Aaron & Dr. Suzanne Siegel  
 Michael & Molly Shapiro  
 A. Jerome & Margaret Crowley  
 Susan & Wm. Wesley Grover  
 Jill & Chirs Newton  
 Scott & Margaret Wilson  
 J. Christopher & Jan Rabin  
 Stephen & Christina Acampora  
 Carrie & Thomas Buchwald  
 Peter & Jan Lamberti  
 Glenn & Shirley Demichele  
 Daniel Pinsel  
 Dr. Dickie Kay  
 Maarten & Anne Van Gerven  
 Brian & Jodi Manion  
 M. Vecchione  
 David & Kristen Randall  
 Dawn Weiland  
 Greg & Susanne Immell

*For Jack Greeley's Family Fun Day in honor of Jack Greeley (cont.):*

Patrick & Laura Sack  
 John & Patricia Jilek  
 Dr. George & Dr. Denise Hefner  
 David & Katherine Walter  
 Michael & Jennifer Qualley  
 Mark & Mindy Leonard  
 Michael & Julie Muth  
 Melissa & Steven Osuch  
 Kenneth & Kelly Goldberger  
 Gary & Leah Kieffer  
 Scott & Kimberly Bryant  
 Gary & Sarah Cohen  
 Martin & Mary Phelps  
 Oscar & Julia Izquierdo  
 Marcia Elkin  
 Douglas & Amy Klein  
 Michael & Eliisa Capstick  
 Ken & Ann Van Overberghe  
 Diane & Marco Laudati  
 Edward & Paige Werner  
 Thomas & Jennifer Conway  
 Susan Durlacher  
 Jodi Pauly  
 Robert & Lisa Lewis  
 Peter & Stacy Walsh  
 Richard & Patricia Arndt  
 Richard & Patricia Arndt  
 Steven & Lynn Gackenback  
 Scott & Tamara Stensby  
 Michele & Larry Rivkin  
 Susan Ries  
 Louis & Mara Grujanac  
 Carmen Morin  
 Alex & Nancy Jarett  
 Hisashi & Carol Watanabe  
 Richard & Elizabeth Brandt  
 Susan & James Wynne

*For Jack Greeley's 7th Birthday:*

Dorothy & John Joyce  
 Bryan Pettas  
 Alex & Marie-Jeanne Kaparos  
 Tim Meyers  
 Gary & Diane Schiappacasse  
 Robin Woith Dallas Cowboys  
 Larry Mayer  
 Ryan Huzjak  
 Anna Pettiti NFL

## Gifts and Donations

*For the Cystinosis Fun Run/Walk in honor of Kacy Wyman:*

Nichol Stanley  
 John & Elizabeth Shabino  
 Janet & Joel Caloia  
 Jessica Carmichael  
 Michael & Amy Fitzpatrick  
 Shari Dobrusin  
 Larry & Elizabeth Schrock  
 Sandra Adams  
 Margaret Zidar  
 James & Marilyn Schelberg  
 Tamara Davidson  
 Carolyn Wheeler  
 Kaarin & Edward Averill  
 Sandra Adams  
 Kelley McDonald  
 Lynn Margolis  
 Lawrence Barnett  
 Elizabeth Jinnett  
 Bridget Reynaert  
 Shelley Aurit  
 Nichol Stanley  
 Deane Spors  
 Randy & Jennifer Blomberg  
 Shelley Aurit  
 Maire Grant  
 Jeanette Sloan  
 Jerome & Laurie Rosenthal  
 Charlotte & Dallas Haun  
 Joseph & Linda Tuthill  
 Barbara Benhanan  
 Timothy & Janis Casai  
 Kim & Randall Hawes  
 David & Vicki McLellan  
 David & Vicki McLellan  
 Robert Kosen  
 David & Vicki McLellan  
 Christine Lussier  
 Paul & Randee Freedman  
 Maria Cooney  
 Jonathan & Janette Frank  
 Steven & Beth Fine  
 George & Patricia George  
 Sarah & Timothy Davidson  
 Adam & Nancy Forster  
 Tammy & Victor Torres  
 Dale & Corrinne Parker  
 Dale & Corrinne Parker  
 Dale & Corrinne Parker  
 Dale & Corrinne Parker  
 Robert & Cindy Firsten

*For the Cystinosis Fun Run/Walk in honor of Kacy Wyman (cont.):*

Betsy & Thomas Walbridge  
 Delynn Anderson  
 Laura Vaughn  
 Peggy Gerwitz  
 Paul & Maureen Kaplan  
 Mark & Terri Morawski  
 Jennifer Thompson  
 Laura & Barry Ruppenthal  
 Charles & Marsha Bishop  
 William Eagan  
 Ronald & Marilyn Gunther  
 David & Vicki McLellan  
 John & Beth Dumala  
 Steven & Mary Jakubiec  
 Mark & Anne Campbell  
 Calvin & Jennie Perry  
 Miriam Halprin  
 Charlotte & Dallas Haun  
 Deborah & Kenneth Hamel  
 Arthur & Marjorie Levine  
 Ronald & Marilyn Gunther  
 Christopher & Donna Donnelly  
 Elaine Darbee  
 David & Sherise Levine & Lee  
 Margo Miller  
 William & Sandra Lefkofsky  
 Michael & Ann McGovern  
 Sheryl Saperstein TTEE  
 Robert Renchik  
 Dennis & Elizabeth Kavanagh  
 Jeffrey & Cindy Diskin  
 Richard Copes  
 Sonia Gonie  
 Dale & Corrinne Parker  
 Ronald & Georgina Whitaker  
 James O'Brien  
 Randy & Kimberly Chudler  
 Amy Anstett  
 William & Marie Emrick  
 Mark & Cynthia Kandel  
 Jena & Gordon Brant  
 Alan & Gayle Cutler  
 Kim Gladstone  
 Jane Sowers  
 Lynda Czeizler  
 Daniel & Vicki McLellan  
 Grant & Melissa Williams

*For the Cystinosis Fun Run/Walk in honor of Kacy Wyman (cont.):*

Katherine & Timothy Kenum  
 Arthur & Marjorie Levine  
 R. Prewitt  
 Jeffrey Burmeister  
 Mark & Deborah Simpson  
 Eric Schultz  
 Paul & Carrie Manz  
 John & Nazik Kissinger  
 James & Charlene Yetter  
 Gary & Gayle Samuels  
 Larry & Suzi Dell  
 Elaine Darbee  
 Sherie & Randy Eschels  
 Timothy & Carrie Celovsky  
 Marcy & John Gottesman  
 Mark Bowman  
 Sandra Adams  
 Dave & Amy Scott  
 Robert & Ilene Darbee  
 Garry & Brenda Kepes  
 William & Christina Parker  
 Randy & Jennifer Blomberg  
 Seth & Christa Shilling  
 Renee Apkarian  
 Mark & Jennifer Zobl

*For the C.H. Robinson Golf Tournament in honor of Tahnne Woodward:*

Arnulfo Sifuentes  
 Mary Murphy  
 Dianna & Kenneth Neukircher  
 Nielsen & Co.  
 Jacqueline Jones  
 Jason & Alicia Madsen

*For Leombrunville in honor of Paula Shal:*

Jan & Jerry Frye  
 Mike & Darcie Feltmeyer  
 Peggy & Douglas Groebner  
 Dirk & Jennifer Meminger  
 William & Susan Janssen  
 Kerry & Kathy Wickler  
 James & Sharie Nelson  
 Amy Dusavage

## Gifts and Donations

*For Carnival for a Cure in honor of Alexis and Evan LeBeau:*

Sharon Riegert  
Robert & Bridget Bachara  
Sherry Jopp  
George & Kelly Miller  
Michael Chiarito  
Joan Jocke  
Candy & Mike Manning  
Steven & Jennifer Nenn  
Philip & Marlene Herbert  
Christine Riso  
Kathy McKinney  
Karen Larsen  
Alina Haber-Kovach  
Lisa Byrne  
Linda Pomianowski  
Michelle Ashby  
Dave & Jennifer Ostermeier  
James & Beverly Ruhl  
Gina Wehde  
David & Stephanie Hulthen  
Nan Drummond  
Ari & Cemak Loghmani  
Steve & Connie Ondrus  
Denise Chevalier  
Sharon Burnham  
Thomas & Kelley Kunkel  
Eric & Maria Risch  
Andrea & Mike Teska  
Pauline & Thomas Fraiser  
Amanda Hausner  
Kari & Jayson Berg  
Kristin Plock  
Nadia & Thomas Tapp  
Chad & Lisa Simon  
William & Jennifer  
John & Kathy Paoello  
Nick & Julie Giannasi  
Dave & Theresa Wilson  
Dan & Michelle Lettieri  
Joe & Marianne Welps  
Sonja Hardy  
Diana Schnibben  
John & Lisa Endrud  
Kathy Aguayo  
Bob & Paulette Campbell  
Daniel & Kelly Makar  
Bruce & Bonnie Marshall

*For the Wysocki Boys' Birthdays in honor of Jacob Ellerbrock:*

Theresa Osenkarski  
Kenneth & Lori Hogan  
Tarek & Heather Koch  
Jeff & Mary Ellerbrock  
Jonathan & Sascha Friedman  
Corrine & Daniel Taber

### Personal Health Records

Do you or your child have a personal health record that you carry to doctor's appointments, emergency room visits, etc.? A personal health record can save time and ensure medical professionals receive accurate information. Many medical professionals appreciate when patients with cystinosis bring updated, typewritten personal health records to their attention. A personal health record can include patient contact information, emergency contact information, diagnoses, symptoms, surgeries, medications, allergies, vaccinations, insurance information, physician information, and more. Don't forget to include the CRN's web address ([www.cystinosis.org](http://www.cystinosis.org)) so that your medical professionals can find out more about cystinosis! For a good example of a personal health record form, go to:

<http://www.cystinosis.org/Emergency%20Medical%20Form.pdf>

### Eye Drop Resources

The following contacts may be able to help patients with cystinosis obtain cysteamine eye drops:

National Institutes of Health (NIH) Eye Clinic  
Casey Hadsall  
(301) 594-3141  
[cferguson1@cc.nih.gov](mailto:cferguson1@cc.nih.gov)

Leiter's Pharmacy  
1700 Park Avenue Suite 30  
San Jose CA 95126  
toll free 800-292-6773  
or 408-292-6772  
[www.leiterrx.com](http://www.leiterrx.com)

Terre Haute Prescription Shop  
Terre Haute, IN  
John Love  
(812) 232-9646

Aurora Pharmacy  
3284 W. Main St.  
East Troy, WI 53120  
(262) 642-5800

### Organ Donor Tax Credits

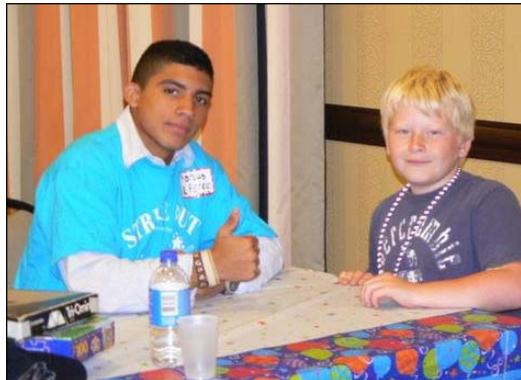
Did you know that some states offer benefits to living organ donors, including tax credits? Some states include Arkansas, Georgia, Iowa, Minnesota, Mississippi, New Mexico, New York, North Dakota, Ohio, Oklahoma, Utah, Wisconsin. For a complete list of states and benefits, go to:

<http://www.transplantliving.org/livingdonation/financialaspects/statetax.aspx>

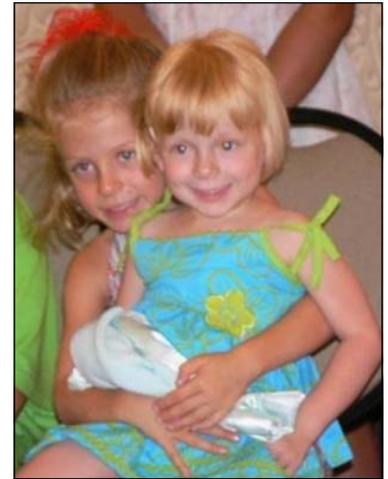
## 2007 CRN Family Conference Photos



*Ashley and Tammy Bridwell,  
Mack Maxwell, and Paula Shal*



*A child care volunteer and  
Patrick Jordan*



*Taylee and Kenadee Julian*

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## CRN Executive Committee Meets in Chicago



*The CRN Executive Committee had a rare face-to-face meeting Oct. 19-21 in the Chicago area. Executive Committee members include from left to right: Brittney LeBeau-Treasurer, Christy Greeley-President and Executive Director, Elva Smith-VP Research, Jill Morrill-VP Development, Pam Woodward-VP Family Support, Karen Gledhill-Secretary, and Paula Shal-VP Education & Awareness*

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

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

**Mark your calendars**

**June 27-28, 2008**

5th International Cystinosis  
Conference in Dublin, Ireland

**2009**

CRN Family Conference in Atlanta, Georgia

**August, 2010**

International Pediatric Nephrology  
Meeting in New York City

More information on these events will be at  
[www.cystinosis.org](http://www.cystinosis.org) as it becomes available.