CRN Family Conference: Heroes Among Us July 18-20 in D.C.

The Cystinosis Research Network (CRN) is pleased to announce that the 2013 Family Conference will be held July 18-20, 2013 at the Washington Marriott Wardman Park Hotel in Washington, D.C. This will be CRN’s sixth family conference.

We hope you will plan to join us and learn about the latest updates in cystinosis research through lectures, workshops, poster sessions, and medical and patient panels. There will also be opportunities to socialize with other patients and families, which will provide valuable connections and friendships that will last a lifetime. This is a great chance to meet others who are walking in your shoes.

CRN is committed to providing family support to those living with cystinosis. The family conference brings families and the medical community together to share hope and support.

CRN has budgeted for a limited number of Conference Scholarships to help families/individuals attend the Family Conference. For more information, see http://bit.ly/14wzEqt. (See Family Conference, page 10)

Sigma-Tau Pharmaceuticals Launches Cystaran™ for Corneal Cystine Accumulation

Press Release—May 1, 2013
GAITHERSBURG, MD, May 1, 2013—Sigma-Tau Pharmaceuticals, Inc. (Sigma-Tau), a part of the Sigma-Tau Group Rare Disease Franchise, announced today the availability of CYSTARAN™ (cysteamine ophthalmic solution) 0.44%, the first and only FDA-approved therapy for the treatment of corneal cystine crystal accumulation in patients with cystinosis. Sigma-Tau developed CYSTARAN in partnership with the National Institutes of Health (NIH) and in cooperation with the Cystinosis Foundation, the Cystinosis Research Foundation, and the Cystinosis Research Network. The U.S. Food and Drug Administration (Continued on page 4)
To the cystinosis community,

With spring upon us and the summer months shortly ahead, there are not many situations where a person in his professional or civic activities has an opportunity to frequently represent and tell an ongoing story of dedication and perseverance. Being the current President of Cystinosis Research Network, I have been provided that opportunity on a number of occasions over the last few months.

In January, my wife Katie and I, along with nine other families, went to Washington, D.C. to meet with approximately 40 legislative aides. The participating families represented the cystinosis community, not a particularly advocacy group. Our goals were to reinforce the benefits of the Orphan Drug Act of 1983, give unwavering support for the programs and services within the National Institute of Health, advocate the expansion of the Katie Beckett waiver rules, and promote involvement by House of Representative members in the Rare Disease Caucus. A good number of spirited conversations were covered in that trip, but to one and all, a realization was made that consistent follow up is needed to remain “top of mind” in Washington, D.C.

In February, I returned to Washington, D.C. with some Board members for a strategic planning meeting and to get a sense of the layout for the upcoming Family Conference. Details regarding the Conference are provided throughout the newsletter; it will be grand. The strategic planning meeting reinforced the commitment to the vision of Cystinosis Research Network—the acceleration of the discovery of a cure, development of improved treatments, and enhancement of quality of life for those with cystinosis.

When I referred earlier to dedication and perseverance, we recognize the daily challenges that are overcome by cystinosis patients and caregivers. It is also important that we communicate our gratitude to the pharmaceutical companies who extend an abundance of time, energy and spirit to support a mission similar to CRN. We tip our caps to Sigma Tau Pharmaceuticals for their drive to make ophthalmic cysteamine, Cystaran, commercially available and to Raptor Pharmaceutical for securing Food & Drug Administration approval for Procysbi, a delayed-released cysteamine medication. Both of these products will provide an enhancement to the quality of life for those with cystinosis.
In April, Raptor Pharmaceutical invited our family to participate in their corporate launch meeting for Procysbi. Many within Raptor had not had an opportunity to spend time or hold conversations with patients with cystinosis even though they had been engaged in the manufacturing of an improved treatment medication. Representatives from the Cystinosis Foundation and Cystinosis Research Foundation were also in attendance and we collectively expressed the ongoing efforts of families and advocacy groups to support the past and present work of all beneficial treatments.

In May, members of the cystinosis community will gather again in Washington, D.C. for the National Organization of Rare Diseases Annual Gala. Honors will be bestowed on Dr. Jess Thoene and Sigma Tau Pharmaceuticals for their commitment to the rare disease community. Our cystinosis community has been a direct beneficiary of the successful work completed by Dr. Thoene and Sigma Tau. It will be an honor to attend this event representing Cystinosis Research Network and to express my gratitude as a parent of a child with Cystinosis, Sarah (age 7).

Cystinosis Research Network is pleased to present the 6th Family Conference in Washington, D.C. at the Marriott Wardman Park on July 18-20. The initial outreach from the cystinosis community has been tremendous. A comprehensive agenda has been developed by the Family Conference Committee that will provide the attendees with an exhilarating experience and a confidence that the future for the cystinosis community will continue to brighten. I am truly looking forward to an active role in the 2013 Family Conference.

As I referenced in my first President’s letter, each Board Member and Committee Member for Cystinosis Research Network feels deeply in their hearts that their involvement is for a reason and has purpose. CRN always needs to have more families involved. Participation is contagious, so be a part of building the momentum for the cystinosis community.

Warmest regards,

Jeff Larimore
President

Cystinosis Parent Handbook


The Cystinosis Parent Handbook is a tool for families to use in their journey after receiving a diagnosis of cystinosis. Families are likely filled with questions about the disease and the future of their child’s life. The Handbook will help families gain a better understanding of cystinosis and its treatment, learn to care for their child and find support from others in the cystinosis community. Families may want to keep the Handbook as a reference over the coming years.

The Cystinosis Parent Handbook was written with input from many members of the cystinosis community and the following contributors of the Parent Handbook Committee: Jean Blum, Maya Doyle LCSW, Christy Greeley, Colleen Hammond, Lauren Hartz, Jessica Britt Jondle, Marybeth Krummenacker, Katie Larimore, Mack Maxwell, Frankie McGinnis, Terri Schleuder, Steve Schleuder, Serena Scott, Sue Scott, Garrett Thomas, Lynn Thomas, Pam Woodward, Tahnie Woodward, and Jen Wyman.
Sigma Tau Launches Cystaran™
(continued from page 1)

(FDA) approved CYSTARAN in October 2012, and the product has also been granted Orphan Drug status.

In connection with its product launch, Sigma-Tau has established the CYSTARAN Hotline which is administered by Accredo Specialty Pharmacy and staffed by pharmacists, registered nurses, and specialists who are trained to coordinate the delivery of CYSTARAN directly to patients, provide reimbursement support, and offer pharmacy services. Patient assistance programs for CYSTARAN are also available, including co-pay assistance for eligible patients and access to CYSTARAN therapy for uninsured or under-insured patients. Patients, caregivers, and physicians in the United States and Puerto Rico can access the CYSTARAN Hotline at 1-800-440-0473, or by visiting the Accredo website, www.Accredo.com.

“The CYSTARAN launch marks an important milestone for Sigma-Tau and further demonstrates our proven ability to develop and deliver novel therapies for patients suffering from a wide range of rare diseases,” noted Dave Lemus, Chief Executive Officer of Sigma-Tau. “Sigma-Tau is committed to ensuring comprehensive access for all cystinosis patients with corneal crystal accumulation, and we feel especially privileged to be able to offer this critical new therapy which will make a positive impact on these patients’ daily lives.”

“For the hundreds of children and adults in the United States who suffer from corneal cystine crystal accumulation as a result of cystinosis, the commercial availability of CYSTARAN provides access to a critically needed therapy,” commented Craig B. Langman, MD, the Isaac A. Abt, MD Professor of Kidney Diseases and Head of Kidney Diseases at the Ann & Robert H. Lurie Children’s Hospital of Chicago and the Feinberg School of Medicine of Northwestern University. “We need to make sure that physicians and patients managing cystinosis understand the risk of eye complications and are aware of the availability of an FDA-approved therapy with documented safety and effectiveness.”

CYSTARAN is available as a sterile ophthalmic solution containing 6.5 mg/mL of cysteamine hydrochloride equivalent to 4.4 mg/mL of cysteamine (0.44%). For full prescribing information for CYSTARAN, see www.cystaran.com

Safety: The most frequently reported ocular adverse reactions occurring in ≥10% of patients were sensitivity to light, redness, eye pain/irritation, headache, and visual field defects.

For enrollment, ordering, and prescription information, please visit the Cystinosis Research Network’s eye drop page at www.cystinosis.org/family-support/eye-drops
FDA Approves Procysbi™ for Cystinosis

Press Release—April 30, 2013

The U.S. Food and Drug Administration today approved Procysbi (cysteamine bitartrate) for the management of nephropathic cystinosis in children and adults. Procysbi was granted orphan product designation because it is intended to treat a rare disease or condition.

Currently the FDA approved drugs used to treat cystinosis include Cystagon (cysteamine bitartrate), an immediate-release tablet that was approved in 1994, and Cystaran (cysteamine ophthalmic solution) eye drops, approved last year to treat corneal cystine crystal accumulation.

Procysbi is a delayed-release capsule intended for patients ages 6 years and older. While Cystagon is taken every six hours around the clock to control cystine levels, Procysbi is a long-acting formulation that is taken every 12 hours.

“Procysbi is the only delayed-release product approved by FDA to treat nephropathic cystinosis, offering patients with this rare disease an important new treatment option,” said Andrew E. Mulberg, M.D., deputy director, Division of Gastroenterology and Inborn Errors Products, Center for Drug Evaluation and Research, FDA.

The major study supporting Procysbi’s safety and effectiveness involved 43 adult and pediatric patients with nephropathic cystinosis. Patients were randomly assigned to receive Cystagon or Procysbi for three weeks before being switched to the other product for an additional three weeks. Blood testing showed Procysbi was as effective as Cystagon in controlling cystine levels.

Roundup a Cure for Cystinosis, Facebook Auction, and Letter Donations

by Deb Reed—Board Member

The Reed families joined together for a Facebook auction and fundraiser for cystinosis in honor of Mason Reed.

The auction had donated items, some homemade pies, and homemade wares from talented friends and some services given as well. Other generous donations we offered were a Dallas Cowboys signed football and cheerleaders’ picture, as well as a Tampa Bay Buccaneers signed football. Also special donations of two Texas flags, both flown over the Capitol of Texas with special recognition to Mason and cystinosis.

This fun effort was a huge success and raised a total of $3,100 for cystinosis research!
The Cystinosis Advocate

Capitol Hill Day, Washington, D.C.
January 28, 2013

by Terri Schleuder—Secretary

My son, Steve, and I arrived at the Liason Hotel in Washington D.C. early Sunday afternoon. It is located just 2½ blocks away from the Capitol building, whose dome glowed in the afternoon sunlight, looking almost close enough to touch. We stood in awe at the sight and felt a little like being inside of a picture postcard. After settling in our room we took advantage of the relatively warm, sunny day and set off toward the Capitol and historic Mall, camera in tow.

We spent the next few hours taking pictures and exploring the National Art Museum. With Steve’s many trips to the NIH over the years we’ve been to D.C. several times, but never to the Museum of Art. Steve is a Graphic Design major and really enjoyed the chance to see the incredible exhibits displayed there.

We returned to the hotel in time to freshen up, join our group, and prepare for the purpose of this trip. Steve and I were one of ten families representing Cystinosis Research Network, Cystinosis Foundation, and Cystinosis Research Foundation who along with Raptor Pharmaceuticals, had come together to talk with members of Congress about issues affecting those with rare disease. Specifically, we wanted to share our stories and ask for continued congressional support of the Orphan Drug Act (ODA). Passed in 1983, this legislation is crucial to bringing orphan drugs that treat rare diseases to market. Cystinosis has certainly benefited from the ODA, with the FDA approvals of Cystagon, Cystaran, and Procysbi (Raptor’s delayed-release cysteamine approved three months after our trip to Capitol Hill). We also wanted to ask for continued funding of the NIH, where so much cutting-edge research occurs that benefits so many.

After a delicious meal and a chance to visit with other CRN families, including Jeff and Katie Larimore, Jim and Paula Shal, Lynn and Garrett Thomas, as well as new friends from CF and CRF, we all listened to a presentation by Kevin Brennan and Isa Mirza, from Foley Hoag. These wonderful, personable gentlemen gave us all a crash course in how to effectively share our stories and purpose with the congressional offices we would visit the next day.
As we returned to our room that night I was struck by two things: Steve was very calm and relaxed, and I was terrified. For me this experience was stepping way out of my safe little box, but I realized what an important opportunity was being given to us. It was a chance to be ‘heard’ by people who have the power to make a difference for all those with rare disease. That night we practiced and practiced what we wanted to say and I breathed…deeply, many times. By morning the words were there and we were ready.

After an amazing breakfast that included freshly squeezed orange juice and coffee so good I almost cried, we all boarded a shuttle and headed to the Capitol steps for a group photo. I will say the beautiful, warm, sunny day of 24 hours before had morphed into a cold, gray, rainy day with a biting wind. We all made the best of it and huddled close under several black umbrellas as the photographer snapped several pictures.

Each of the ten families representing the cystinosis community were scheduled to meet with three or four different congressional offices, including those from their home states. In all, the offices of 36 senators and congressmen were visited by our group on Monday, January 28. Steve and I, who are from Michigan, met with the legislative assistants from Senator Debbie Stabenow (D-MI), Senator Carl Levin (D-MI), Rep. Kerry Bentivolio (R-MI), and Rep. Rosa DeLauro (D-CT).

Each time we told our story and asked for support of the Orphan Drug Act and continued NIH funding, we were welcomed with compassion, interest and assurance that these issues were important and had the backing of the legislators we visited. With each visit my nervousness eased. Steve, however, was relaxed and calm the whole time and shared his personal story beautifully. I have seldom been more proud of him. At the end of the day we both felt empowered, and heard. It was an incredible experience to feel what you said made a difference.

The day concluded with another delicious meal at the Monocle, a nearby restaurant, and the chance to share stories with the other families and relax. The common theme was that it had been a positive, empowering experience for everyone.

All too soon we headed home filled with wonderful memories. I would like to extend our thanks and gratitude to Patrick Reichenberger and Clair Johnstone and the Cystinosis Foundation for all their efforts in arranging this experience.
Financial Update

by Jenni Sexstone—Treasurer

We are pleased to present the financial results of the Cystinosis Research Network through March 31, 2013. These financials represent the great efforts of all CRN members: patients, parents, family, friends, and researchers focused on educating the public and medical communities and improving quality of life of those with Cystinosis.

For the three months ended March 31, 2013, total income secured is $129,000 and is primarily driven by grants received from Raptor Pharmaceutical and Sigma-Tau Pharmaceuticals. Fundraising efforts contributed to 13% of total funding. Total donations from public support organizations such as United Way, Network for Good, and Facebook represented the remaining 9% of funds secured in the first quarter of 2013.

Total expenses incurred for the three months ended March 31, 2013 were $74,000. Administration, registration, and travel costs associated with Education & Awareness amounted to approximately $5,000 through March 2013 compared with $2,000 through March 2012. Fundraising expenses incurred were $3,000 through March 2013 compared to $10,000 through March 2012. Finally, administrative expenses totaled $13,000 compared with $15,000 for the same period in 2012.

A primary objective of the Cystinosis Research Network is to provide funding for research grants. These programs focus on identifying the underlying effects of cystinosis and expanding outreach and education domestically and internationally. Total grant payments of approximately $53,000 have been made through March 2013. The institutions that have received support from CRN in 2013 include Bambino Gesu Hospital, Rome, Italy; University of Sunderland, Sunderland, Scotland; and VU University Medical Center, Leuven, Belgium. Throughout the newsletter will be more detailed information regarding the status and findings of each of the research programs in progress.

A comparable financial recap for Cystinosis Research Network for the three months ended March 31, 2013 and 2012 is:

<table>
<thead>
<tr>
<th></th>
<th>Jan-Mar 13</th>
<th>Jan-Mar 12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Income</td>
<td>$ 128,501</td>
<td>$ 45,437</td>
</tr>
<tr>
<td>Total Expense</td>
<td>$ 74,086</td>
<td>$ 121,777</td>
</tr>
<tr>
<td>Net Operating Income/(Loss)</td>
<td>$ 55,792</td>
<td>$(76,340)</td>
</tr>
<tr>
<td>Cash on Hand—Jan 1</td>
<td>$ 102,654</td>
<td>$ 212,219</td>
</tr>
<tr>
<td>Net Change in Cash</td>
<td>$ 46,753</td>
<td>$(47,525)</td>
</tr>
<tr>
<td>Cash on Hand—Mar 31</td>
<td>$ 103,941</td>
<td>$ 164,694</td>
</tr>
</tbody>
</table>
Greeley Family Represents CRN and Cystinosis Community at Sigma Tau Annual Meeting

by Christy Greeley—Executive Director

The Greeley family was honored to represent the Cystinosis Research Network and the cystinosis community at Sigma Tau’s annual all-staff meeting in Washington, D.C. on January 25, 2013. To celebrate the approval of Cystaran last October, the company wanted a family living with cystinosis to communicate their story and give a better idea to all Sigma Tau colleagues of how much of an impact their hard work on obtaining approval for the eye drops has had.

Christy gave an overview of cystinosis and the services CRN provides, Dave and Alex gave their own personal experiences living with cystinosis as a father and as a sister, respectively, and Jack thanked Sigma Tau for their contributions to the treatment of his disease. The family went on to celebrate with the team from Sigma Tau that evening. Special thanks to Lesli King for inviting the family to attend and her many years of assistance and service to the cystinosis community.
Attending a family conference can be a financial challenge, especially in today’s economy. Therefore, we have budgeted for a limited number of Conference Scholarships, funded in part by Raptor and the Croce family contribution, to help families/individuals attend the 2013 CRN Family Conference. Conference Scholarships are open to individuals and families affected by cystinosis who are attending the conference. For more information, see [http://bit.ly/14wzEqt](http://bit.ly/14wzEqt).

**Hotel:** Washington Marriott Wardman Park  
2660 Woodley Road NW  
Washington, D. C. 20008

**To Reserve A Room Online Using the Special Conference Site:**  

**To Reserve A Room By Phone:**  
Reservations: 1-877-212-5752 or 1-800-228-9290. Ask for Enhanced Group Reservations, Group Code is “Cystinosis Research Network”  
The CRN block of rooms will be released on June 26th, so please plan to make your reservations before this cut-off date.

**Parking:** $20/per 24-hour period for Attendees (Reg. $34.00)

**Travel:** The closest airport to the Washington Marriott is the Reagan Washington National (DCA) 8 miles; Washington Dulles Airport (IAD) is 24 miles and Baltimore (BWI) is 34 miles

**Ground Transportation:** Metro Stop is located less than ½ block from the hotel

**Meals:** All meals except for dinner on Friday night are included in the registration fee.
- Thursday, July 18 – CRN Welcome Reception (light appetizers and cash bar)
- Friday, July 19 – Complimentary Continental Breakfast
- Friday, July 19 – Complimentary Luncheon
- Friday, July 19 – Dinner on your own
- Saturday, July 20 – Complimentary Continental Breakfast
- Saturday, July 20 – Complimentary Luncheon
- Saturday, July 20 – Complimentary Dinner/Party

**Registration (includes reception, 2 breakfasts, 2 lunches, and 1 dinner):**
- Early bird registration fee (before June 1st): $50 per individual or household
- Registration fee (after June 1st): $75 per individual or household
# 2013 CRN Family Conference Draft Agenda

## Cystinosis Research Network Family Conference

**July 18 – 20, 2013**  
Marriott Wardman Park Resort  
Washington, D.C.

### AGENDA

**Draft Agenda • 5/3/13**

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**Wednesday, July 17**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Room</th>
</tr>
</thead>
</table>
| 4:00 pm – 8:00 pm | CRN Board of Directors Meeting  
                 Closed Session                                                | Nathan Hale   |

**Thursday, July 18**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:00 pm – 5:00 pm</td>
<td>Registration / Information Desk</td>
<td>Marriott Foyer</td>
</tr>
</tbody>
</table>
| 1:00 pm – 4:00 pm | CRN Scientific Review Board Meeting  
                 Closed Session                                                | Nathan Hale   |
| 5:00 pm – 7:00 pm | CRN Welcome Reception  
                 Complimentary Appetizers, Cash Bar  
                 Hosts: The CRN Board of Directors  
                 Please join us for drinks and appetizers and an opportunity to meet the families and physicians attending the conference. Special surprise guest! | Marriott Foyer|
| 7:30 pm – 9:00 pm | Family Introductions  
                 Pam Woodward, CRN Vice President Family Support | Nathan Hale   |

**Friday, July 19**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Room</th>
</tr>
</thead>
</table>
| 7:00 am – 8:15 am | Breakfast –  
                 Complimentary                                                  | Marriott Salon 1 |
| 8:00 am – 5:30 pm | Registration/Information Desk                                | Marriott Foyer|
| 8:00 am – 5:30 pm | Child Care Open                                               | Maryland B/C |
| 8:00 am – 9:00 pm | Teen Lounge Open                                               | Maryland A |
| 8:30 am – 8:40 am | Welcome and Opening Remarks  
                 Jeff Larimore, CRN President                                  | Marriott Salon 1 |
| 8:40 am – 9:00 am | Cystinosis Research Network – Your Advocacy Group  
                 Jeff Larimore, CRN President                                  | Marriott Salon 1 |
| 9:05 am – 9:35 am | All About Cystinosis  
                 William A. Gahl, M.D., Ph.D.                                  | Marriott Salon 1 |
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
</table>
| 9:40 am – 10:00 am | Kidney Disease in Cystinosis  
Frederick Kaskel, M.D., Ph.D. | Marriott Salon 1 |
| 10:05 am – 10:25 am | Pulmonary Issues in Cystinosis  
Richard H. Simon, M.D. | Marriott Salon 1 |
| 10:25 am – 10:40 am | Break                      | Marriott Foyer   |
| 10:40 am – 11:00 am | Gastrointestinal Issues in Cystinosis | Marriott Salon 1 |
| 11:05 am – 11:25 am | Neurological Issues in Cystinosis  
Doris A. Trauner, M.D. | Marriott Salon 1 |
| 11:30 am – 11:50 am | Pediatric Endocrine Issues in Cystinosis  
Craig Langman, M.D. | Marriott Salon 1 |
| 11:55 am – 12:00 pm | Administrative Announcements  
Jeff Larimore, CRN President | Marriott Salon 1 |
| 12:00 pm – 1:00 pm | Luncheon  
Complimentary | Marriott Salon 1 |
| 1:00 pm – 2:00 pm | Poster Session  
This session will showcase a mix of science, medicine, industry, advocacy group and patient experiences to provide an interactive experience for both family and professional attendees. Researchers, clinicians, industry, advocacy representatives, students, patients, and caregivers will be invited to exhibit their latest research findings, treatment breakthroughs, advocacy group updates and real patient and family experiences. This will be an interactive session where exhibitors will be available to discuss their work or experiences with those attending. We invite you to browse the posters and take this opportunity to ask the authors and presenters questions. | Marriott Foyer   |
| 2:15 pm – 2:45 pm | NIH / Cystinosis Research Network Cystinosis Fellow  
Galina Nesterova, M.D. | Marriott Salon 1 |
| 2:50 pm – 3:10 pm | Gene Therapy in Cystinosis  
Stephanie Cherqui, Ph.D. | Marriott Salon 1 |
| 3:15 pm – 4:15 pm | Medical Panel  
Moderator: William A. Gahl, M.D., Ph.D.  
Panelists: Bruce Barshop, M.D., Rachel Bishop, M.D., Leicia Belmont, M.D., Fabio Candotti, M.D., Stephanie Cherqui, Ph.D., Ewa Elenberg, M.D., Paul Goodyer, M.D., Laurence Greenbaum, M.D., Ph.D., Julie Ingelfinger, M.D., Frederick Kaskel, M.D., Ph.D., Robert Kleta, M.D., Ph.D., Craig B Langman M.D., Elena Levitchenko, M.D., Ph.D., Roslyn B. Mann, M.D., Galina Nesterova, M.D., Jerry Schneider, M.D., Richard H. Simon, M.D., Jess G. Thoene, M.D., Doris A. Trauner, M.D.  
Please join the entire group for the unique and informative opportunity to have your questions and concerns addressed by the leading physicians and researchers in cystinosis. All of the doctors who have presented at the Family Conference, all attending Medical Advisory Board and Scientific Review Board members, as well as other health care professionals involved in treating and researching cystinosis are scheduled to participate. Questions for the panel will be collected during the proceedings today. | Marriott Salon 1 |
| 4:15 pm – 5:00 pm | Gene Therapy / Stem Cell Discussion  
Moderator: William A. Gahl, M.D., Ph.D  
Panelists: Fabio Candotti, M.D., Stephanie Cherqui, Ph.D., Rick Kaskel, M.D., Ph.D., Jess Thoene, M.D. | Marriott Salon 1 |
| 5:05 pm – 5:15 pm | Reed Family Presentation  
Deb Reed and Family | Marriott Salon 1 |
| 5:20 pm – | Session Wrap Up | Marriott Salon 1 |
## Conference Draft Agenda (cont.)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>5:30 pm</td>
<td>Jeff Larimore, CRN President</td>
<td>Salon 1</td>
</tr>
<tr>
<td>5:30 pm – 5:45 pm</td>
<td>Group Photo Group photos will be taken of all those with cystinosis, as well as all families and professionals in attendance.</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td></td>
<td><strong>Dinner is on your own tonight</strong></td>
<td></td>
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<tr>
<td><strong>Saturday, July 20</strong></td>
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<td></td>
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<tr>
<td>7:00 am – 8:00 am</td>
<td><strong>Breakfast</strong> Complimentary</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>8:00 am – 8:30 am</td>
<td><strong>Registration/Information Desk</strong></td>
<td>Marriott Foyer</td>
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<tr>
<td>8:00 am – 5:30 pm</td>
<td><strong>Child Care Open</strong></td>
<td>Maryland B / C</td>
</tr>
<tr>
<td>8:00 am – 5:30 pm</td>
<td><strong>Teen Lounge Open</strong> Teens are welcome to spend time in the teen lounge anytime. Snacks and drinks will be available, as well as video games and television.</td>
<td>Maryland A</td>
</tr>
<tr>
<td>8:30 am – 8:45 am</td>
<td><strong>Opening Comments</strong> Jeff Larimore, CRN President and Terri Schleuder, CRN Secretary</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>8:50 am – 9:10 am</td>
<td><strong>Cystaran™ (Cysteamine Hydrochloride Ophthalmic Solution) Update</strong> Lesli King, Sigma Tau Pharmaceuticals and Dr. Rachel Bishop NIH Eye Institute</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>9:15 am – 9:35 am</td>
<td><strong>Raptor Pharmaceuticals Procyelp Update</strong> Craig Langman, M.D. and Ted Daley, President Raptor Pharmaceuticals</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>9:40 am – 10:00 am</td>
<td><strong>Strategies of Successful Families</strong> Maya Doyle, LCSW, ARB</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>10:00 am – 10:15 am</td>
<td><strong>Break</strong></td>
<td>Marriott Foyer</td>
</tr>
<tr>
<td>10:15 am – 10:35 am</td>
<td><strong>Caring for Yourself: Mind Body Self-Care</strong> Gregory Lewis Fricchione, M.D. Massachusetts General Hospital, Benson Henry Institute</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>10:40 am – 11:30 am</td>
<td><strong>Living with Cystinosis Panel</strong> Moderators Maya Doyle, LCSW, ARB Panel presentation during which individuals living with cystinosis will answer prepared questions and address topics related to the use of coping mechanisms through the ups and downs that cystinosis brings related to not only developmental and transitional issues of daily life but also medical issues. Teens and adults living with cystinosis will be featured and will share how they have recognized and lived to their full potential given the challenges they have faced. Audience participation will be encouraged.</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>11:35 am – 11:55 am</td>
<td><strong>Development Overview</strong> Jose Morales, CRN VP Development</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>11:55 am – 12:00 pm</td>
<td><strong>Administrative Announcements</strong> Jeff Larimore, CRN President</td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>12:00 pm – 1:00 pm</td>
<td><strong>Luncheon - Complimentary</strong></td>
<td>Marriott Salon 1</td>
</tr>
<tr>
<td>1:00 pm – 2:45 pm</td>
<td><strong>Workshop Session A</strong> These topic specific workshops allow families to tailor their conference experience to meet their specific needs. Families will have the opportunity to discuss and share their own experiences regarding the latest research, management techniques, and therapies with leading experts as well as with other families with similar issues and concerns. Sessions will be repeated so that participants may attend more than one workshop.</td>
<td>Break Out Rooms</td>
</tr>
<tr>
<td>Time</td>
<td>Session</td>
<td>Hosts</td>
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<tr>
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</tr>
<tr>
<td>1:00 pm –</td>
<td><strong>A1 - Newly Diagnosed Families</strong></td>
<td>Rachel DeLomba, CRN Board Member and Pam Woodward, CRN VP Family Support</td>
</tr>
<tr>
<td>2:45 pm</td>
<td></td>
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</tr>
<tr>
<td>1:00 pm –</td>
<td><strong>A2 – Childhood Issues</strong></td>
<td>Jen Saxstone, CRN Treasurer and Deb Reed, CRN Board Member</td>
</tr>
<tr>
<td>2:45 pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1:00 pm –</td>
<td><strong>A3 – Neurological and Educational Issues</strong></td>
<td>Christy Greeley, CRN Executive Director and Britney LeBeau, CRN Board Member</td>
</tr>
<tr>
<td>2:45 pm</td>
<td></td>
<td></td>
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<tr>
<td>1:00 pm –</td>
<td><strong>A4 – Transplantation</strong></td>
<td>Marybeth Krummenacker and Richard Jordan, CRN Board Members</td>
</tr>
<tr>
<td>2:45 pm</td>
<td></td>
<td></td>
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<tr>
<td>1:00 pm –</td>
<td><strong>A5 – Adult Issues</strong></td>
<td>Jessica Jondle, CRN VP Education and Awareness</td>
</tr>
<tr>
<td>2:45 pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1:00 pm –</td>
<td><strong>A6 – Caring for Yourself: Mind Body Self-care</strong></td>
<td>Colleen Hammond</td>
</tr>
<tr>
<td>2:45 pm</td>
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<td></td>
</tr>
<tr>
<td>2:45 pm –</td>
<td><strong>Break</strong></td>
<td></td>
</tr>
<tr>
<td>3:00 pm –</td>
<td><strong>Workshop Session B</strong></td>
<td></td>
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<tr>
<td>4:30 pm</td>
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<td></td>
</tr>
<tr>
<td>3:00 pm –</td>
<td><strong>B1 - Newly Diagnosed Families</strong></td>
<td>Lynn Thomas, CRN Board Member and Pam Woodward, CRN VP Family Support</td>
</tr>
<tr>
<td>4:30 pm</td>
<td></td>
<td></td>
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<tr>
<td>3:00 pm –</td>
<td><strong>B2 – Childhood Issues</strong></td>
<td>Jen Wyman, CRN Board Member</td>
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<tr>
<td>4:30 pm</td>
<td></td>
<td></td>
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<tr>
<td>3:00 pm –</td>
<td><strong>B3 – Neurological and Educational Issues</strong></td>
<td>Jeff Larimore, CRN President and Kathy Mandrell, CRN Board Members</td>
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<tr>
<td>4:30 pm</td>
<td></td>
<td></td>
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<tr>
<td>3:00 pm –</td>
<td><strong>B4 – Transplantation</strong></td>
<td>José Morales, CRN VP Development</td>
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<tr>
<td>4:30 pm</td>
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<tr>
<td>3:00 pm –</td>
<td><strong>B5 – Adult Issues</strong></td>
<td>Terri Schleuder, CRN Secretary</td>
</tr>
<tr>
<td>4:30 pm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3:00 pm –</td>
<td><strong>B6 – Caring for Yourself: Mind Body Self-care</strong></td>
<td>Terri Schleuder</td>
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<tr>
<td>4:30 pm</td>
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<tr>
<td>4:45 pm –</td>
<td><strong>Conference Wrap Up and Announcement of the Above and Beyond Achievement Award</strong></td>
<td><em>TBC</em></td>
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Conferece Draft Agenda (cont.)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event Details</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>5:30 pm</td>
<td>Jeff Larimore, CRN President</td>
<td>Salon 1</td>
</tr>
<tr>
<td>7:00 pm –</td>
<td>Farewell Dinner Dance</td>
<td>Marriott</td>
</tr>
<tr>
<td>10:00 pm</td>
<td>Complimentary, Cash Bar</td>
<td>Salon 1</td>
</tr>
<tr>
<td></td>
<td>Please join all conference attendees for dinner, dancing, and fun for all ages</td>
<td></td>
</tr>
<tr>
<td></td>
<td>to celebrate our cystinosis community.</td>
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</tbody>
</table>

Scenes from the 2011 Conference in San Francisco. We hope to see YOU in Washington, D.C. in 2013!

Creative Ways to Raise Funds for the Conference

**Hold a Yard Sale**
The hands-down best way to raise money is to convert stuff you already own into cash. If you have furniture, electronics, children’s items, sports equipment, jewelry, etc. (in other words, the usual clutter that most of us once thought we needed to buy), then a yard sale might just get you some extra funds for attending the conference.

**Frequent Flyer Miles**
Ask others to donate their frequent flyer miles.

**IRS Tax Deduction**
The IRS will allow parents to deduct some of the costs associated with attending medical meetings related to their child’s health condition. Check [www.irs.gov](http://www.irs.gov) for the latest information.

**Develop a conference pledge sheet**
This is a great way to raise $425 in just one week!
- Day 1: Sponsor yourself – pay the fundraising kitty $25
- Day 2: Ask five friends to contribute $20
- Day 3: Ask two relatives to sponsor you for $25
- Day 4: Ask five co-workers to sponsor you for $10
- Day 5: Ask five neighbors to sponsor you for $25
- Day 6: Ask your company to sponsor you for $25
- Day 7: Ask two businesses you frequent (such as your dry cleaner, doctor, dentist, etc.) for $25

Most people are happy to give when they are asked. Explain the importance of attending the conference. Take the opportunity to raise awareness of Cystinosis in your community. Many people who have raised funds have commented how much others want to help. Other people want to do something positive for you!

**Sold Stuff on Craigslist or eBay**
A good alternative to the yard sale is to make use of Craigslist and eBay. Both are great internet sites for buying and selling almost anything. Over 40 million people use them every month. Craigslist is free and localized, so there is typically no shipping involved. eBay offers several different fee structures based on your needs.

**BE CREATIVE!**
Ask for contributions in lieu of birthday, anniversary and other special occasion gifts.

**Check with Civic Organizations**
Funds can also be found by contacting the local United Way, the March of Dimes, Kiwanis, Rotary, Lions Club, American Legion and other community and civic organizations.
The Cystinosis Advocate

Research Update

by Colleen Hammond—Vice President, Research

The Cystinosis Research Network’s vision is the discovery of improved treatments and ultimately a cure for cystinosis. The Cystinosis Research Network utilizes a Scientific Review Board, comprised of leading experts on the disease of cystinosis, which reviews grant proposals and submits funding recommendations to CRN. More specifically, the Scientific Review Board provides independent, objective review and recommendations regarding each research proposal utilizing grant review guidelines established by CRN and in accordance with the mission of the organization.

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

A major focus of CRN continues to be a determined effort to secure a promising future for the cystinosis community through the support and funding of research grants that lead to improved treatments and ultimately a cure for cystinosis. CRN has funded more than $3 million total in research grants and fellowships. CRN funds a Cystinosis fellowship at the National Institutes of Health. CRN has funded research and education programs in the United States and many countries around the world including Egypt, Mexico, England, Scotland, Italy, Belgium, France, and others. CRN research topics are aimed at every aspect of cystinosis with the purpose of understanding cystinosis and finding improved treatments and a cure. Topics include research and therapies related to neurological, genetic, ophthalmological, gastrointestinal, muscular, nephrology, pulmonary, skin, improved medications, psychological, and much more. A detailed list of specific grants can be found at our website: www.cystinosis.org.

Total New Grants Awarded: $269,510.33

- **Extension of Genotype-Phenotype in Egyptian Patients with Nephropathic Cystinosis.** Neveen Soliman, MD and Elena Levchenko, MD, PhD, Center of Pediatric Nephrology and Transplantation, Cairo University, Egypt and Department of Pediatric Nephrology University Hospitals, Leuven, Belgium. 
  *Total award: $4,389.00*

  *Total award: $54,121.23*
Research Update (cont.)

- **Extension of the Continuation of Feasibility of Cystinosin Replacement Therapy in Cystinosis.**
  Jess G. Thoene, MD, Director, Biochemical Genetics Laboratory, Active Professor Emeritus of Pediatrics, University of Michigan.
  *Total award: $81,000.00*

- **National Institutes of Health 2-year Cystinosis Fellowship.** 2013–2015, Galina Nesterova, MD.
  *Total award: $130,000.00.*

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**Raptor Announces New RP103 (Cysteamine Bitartrate) Delayed-Release Capsules Clinical Trial (RP103-07)**

Raptor is announcing a new clinical trial of RP103 in patients with nephropathic cystinosis. This trial will investigate the 12-hour dosing of RP103 for nephropathic cystinosis compared to the existing immediate-release cysteamine.

**Trial Details**

*Who can participate?*

There are two key criteria: 1) patients must be age 12 or older, and 2) patients must be on a stable dose of immediate-release cysteamine, with average cystine levels higher than 1 nmol ½ cystine/mg of protein over at least two measurements collected during the two years prior to screening. Patients who have undergone a kidney transplant are welcome to participate in the trial.

*How long will the trial be and where will it be located?*

Trial participants will need to visit a clinic 11 times over the course of 7-8 months. The U.S locations are: Emory University in Georgia (study leader—Laurence Greenbaum, MD, PhD), Stanford University in California (study leader—Paul Grimm, MD), Ann & Robert H. Lurie Children’s Hospital of Chicago (study leader—Craig Langman, MD), and Baylor College of Medicine/Texas Children’s Hospital (study leader—Ewa Elenberg, MD). The study will also open at the California Pacific Medical Center (study leader—Minnie Sarwal, MD, PhD). New clinical trial sites in the U.S. and in Europe are going to open soon.

The Cystinosis Advocate

2013 CRN Letter Campaign—Steven Schleuder

by Terri Schleuder—Secretary

A year ago we timidly jumped into our first major fundraising effort for CRN by writing a letter in honor our son, Steven’s, 24th birthday. In it we shared the struggles and joys of daily life with cystinosis. It was a personal, heartfelt story we’d shared many times with family and close friends, but this time it was with a much wider audience. The response raised over $10,000.00 for CRN. We were in awe of the love, kindness, and generosity of so many wonderful people.

This past February we wrote another letter. As this year’s focus, we specifically listed what has been accomplished in 2012 that directly benefits the Cystinosis community. Many years of effort culminated in a staggering list of positive results this past year including:

- A Parent Handbook available on our CRN website;
- The Standards of Care in Cystinosis published by the NIH;
- The FDA approval of Cystaran eye drops by Sigma Tau Pharmaceuticals; and
- The final stages of FDA review of RP103 trademarked as Procybi, a delayed-release formulation of cysteamine by Raptor Pharmaceuticals (approved this year not too long after our letter campaign).

There are many more. To date we are proud and happy to share that over $7,000.00 has been raised this year to help CRN continue in its effort to raise awareness and educate the public and medical professionals about this rare disease, support families as they navigate this difficult lifelong journey, and fund promising research projects that offer better treatment options for those with cystinosis.

We are so grateful and thankful to all who have supported this continuing effort. The generous response of so many continues to humble us. To those who have been thinking about fundraising, but haven’t yet jumped in, know the ability to make a difference always starts with that first step.

Steve Schleuder

Steve (center) with brothers Chris and Eric
Cystinosis Standards of Care

The Cystinosis Standards of Care were written to help individuals with infantile Nephropathic cystinosis, their families, and their medical team. The information presented here is intended to add to conversations with physicians and other health care providers. No document can replace individual interactions and advice with respect to treatment.

One of our primary goals is to give affected individuals and their families greater confidence in the future. With early diagnosis and appropriate treatment, there is more hope today for families with cystinosis than ever before. Research has led to better methods of diagnosis and treatment. Knowledge is increasing rapidly by virtue of the open sharing of information throughout the world among families, health professionals, and the research community.

We acknowledge the important contributions to the Standards of Care of Dr. Galina Nesterova and Dr. William Gahl of the National Institutes of Health, and the members of the Cystinosis Research Network’s Medical and Scientific Review Boards.

Cystinosis Standards of Care are available on the Cystinosis Research Network Website at: https://cystinosis.org/images/what-is/Cystinosis%20Standards%20of%20Care%20June%202012.pdf

Keith and Billy Croce Memorial Scholarship

The Keith and Billy Croce Memorial Scholarship has been established with the Cystinosis Research Network (CRN) to provide financial assistance to families affected by cystinosis. The funds will help with travel expenses for those who wish to attend CRN Family Conferences. The conferences are held at different locations every two years and draw families worldwide. The event allows families to share knowledge, offer support to one another, learn more about new research findings, receive updates from cystinosis organizations from around the world, meet and renew friendships with other families, have the opportunity to participate in research studies, and interact one-on-one with many of the world’s expert clinicians treating and researching cystinosis.

Donations can be sent to:
Cystinosis Research Network
302 Whytegate Court
Lake Forest, IL 60045 USA
Or made through the CRN website via:

Checks payable to CRN—Keith and Billy Croce Memorial
The Greeley family celebrated Jack's 13th birthday this year on St. Patrick's Day in a familiar way—with dinner at his favorite Japanese steakhouse with his Great Grandfather and by sending out the 11th edition of his birthday fundraising letter for the Cystinosis Research Network. Friends and family of the Greeley’s have shown incredible support not only for the family, but for the entire cystinosis community by raising nearly $200,000 since 2003. Following is an excerpt from this year's letter:

A mass uproar ensued in Illinois and elsewhere this past summer when the Powerball jackpot hit $337 million. Like everyone else, we asked ourselves, “What are we going to do with our winnings once our numbers are picked?” Dave posed that question to our almost 13-year-old son, Jack, who gave a classic answer when he declared, “We should donate some money to charity; maybe something that helps animals and the homeless. I would like to get some new (video) games, but that wouldn't take much.” Trust us, he was not kidding.

As most of you know, Jack has cystinosis, a rare metabolic, genetic disease that presented itself 12 years ago. Like the Powerball figures, it has seemed at times that the “numbers” in our life with cystinosis are overwhelming. There are fewer than 500 people in the U.S. with cystinosis and approximately 2,000 worldwide. When he was one, Jack really did not eat solid food for 18 months and vomited 10-15 times per day. He had two feeding tubes that really helped him. Plus, his constant intake of medications 24/7/365 over the past dozen years has been a game changer where Jack is fully mainstreamed in what he does...that’s what swallowing around 100,000 pills and getting up in the middle of the night 4,400 consecutive nights can do for you!

Time flies, so it is crazy to us that we are entering our second decade of writing this letter in celebration of Jack’s birthday upcoming on St. Patrick’s Day. We have enjoyed sharing our story and have appreciated your continued, kind, and generous support. Typically, our letters have framed our journey and retold what Cystinosis has taught and provided us. We thought our letter this year would be more direct and fact-based on some of the great work that the Cystinosis Research Network has accomplished. Most of CRN’s fundraising comes from grassroots levels, like this letter. Through our letter writing efforts over the past 10 years and your commitment and donations, we have raised nearly $200,000. While not $337 million, these funds have made a difference.

We hope you share our pride in these accomplishments. When we decided to begin writing this letter, we did not know what to expect as baring your soul to share something so deeply personal is touchy. Our drive to help Jack, however, over-rode any reservations. In hindsight over the past decade, we have received and hopefully spread so much more than financial support in sharing our story...wisdom, perspective, love, hope, and joy, to name a few.

Jack and others like him have been given a tremendous gift, which is not cystinosis. He
has given all of us a tremendous platform to help us appreciate our own daily lives. That gift from Jack is captured in the words of wisdom and divinity from St. Francis of Assisi, who in part said, "Lord, make me an instrument of Your peace; where this is hatred, let me sow love; where there is injury, pardon; where there is doubt, faith; where there is despair, hope; where there is darkness, light; and where there is sadness, joy...grant that I may not so much seek to be consoled as to console; to be understood as to understand; to be loved as to love; for it is in giving that we receive..." We have received so much in return for sharing our story and we hope it has helped you in some small way."

CRN Cystinosis Awareness Bracelets Are Here!

by Terri Schleuder—Secretary

A big thanks to all who helped raise cystinosis awareness and donate to the Cystinosis Research Network. A "win/win" for everyone! To date, 71 CRN Cystinosis Awareness Bracelets have been sold, which means that $710 has been donated to CRN to further its ongoing mission.

If you haven’t had an opportunity to purchase yours yet, we still have several available, and more can be made as needed. Just $20.00 each, the handcrafted bracelets are made of sparkling Swarovski crystals with silver plated beads and accents. If there is interest, we can customize the bracelets with gold plated beads and accents as well. (I have one and it is beautiful.) Ten dollars for each bracelet sold will continue to be a direct donation to CRN.

Bracelets may be purchased by e-mailing your request and contact information to: tschleuder@cystinosis.org. Please put CRN Bracelet in the subject line. Alternatively, you can fill out the form at the bottom of this article and mail it to me with a check to the Cystinosis Research Network for $20.00 per bracelet. When I receive the order and check, I will mail the bracelet(s) to you.

CRN Cystinosis Awareness Bracelet Order Form

Yes, I would like to order ______ CRN Cystinosis Awareness Bracelets for $20.00 each.

Enclosed is a check to Cystinosis Research Network for: $ ________

Name: ______________________________________________________________

Address: __________________________________________________________

______________________________________________________

E-mail: _________________________ Phone: ______________

Mail to:

CRN Bracelets
c/o Terri Schleuder
40472 Franklin Mill
Novi, MI 48375
RaptorCares provides access and personalized support including:

**Access**

*Reimbursement support* such as prescription services and alternate insurance coverage

*Assistance* with copays, premiums, prescription drug costs, and travel costs for eligible patients

*Distribution support* to make it easy for you to fill your prescription

**Adherence**

*Personalized treatment support*, including:

- Outreach from RaptorCares nurses
- Emails and materials sent right to you that support your current needs
- Community-inspired tips and tools to help make your life more manageable

**Enroll in RaptorCares:**

If you want to enroll in RaptorCares today, or you are not certain if you are already enrolled, call **855.888.4004** (Monday–Friday, 8:00 AM – 7:00 PM CST) and a RaptorCares Case Manager will assist you.

Enroll directly online at [RaptorCares.com](http://RaptorCares.com) and learn more about program benefits.

You may un–enroll at any time by visiting RaptorCares.com/unsubscribe.php or calling 855.888.4004.
Raptor continues to assist the cystinosis community
Raptor helps patients and caregivers by providing education and resources through the comprehensive patient support program called RaptorCares, which was created for—and with input from—the nephropathic cystinosis community.

RaptorCares provides ongoing support and information, customizable nephropathic cystinosis education resources, email support with helpful information for managing nephropathic cystinosis, and more resources and tools will be coming soon.

Raptor and the CRN look ahead
Raptor would like to thank the cystinosis community for its support and partnership over the years. Raptor is also thankful for the opportunity to partner with CRN and supports CRN’s mission to advocate for research, provide family assistance, and educate the public and medical communities about cystinosis. Raptor looks forward to the sixth Family Conference this July in Washington D.C., where families can meet, renew friendships, and interact with many of the world expert clinicians treating and researching cystinosis today.

Alex (L) and Jay (R) Newcomb
Nelly DaLomba
Fidelity Goodridge
CRN Development Update

By José Morales—Vice President, Development

I was approached by Jeff Larimore regarding the possibility of assuming the Vice President of Development responsibilities earlier this year and decided to accept. My decision was based on the belief in the importance and critical contributions the Cystinosis Research Network organization has made, is making, and will continue to make. I officially assumed the Vice President of Development responsibilities on February 24, 2013 and have spent the last few weeks assessing our programs and initiatives. I am so excited about having the opportunity to serve the cystinosis community in this capacity. My first priority has been to define the Development Committee’s organization, establish a priority of work, and create consistent operating protocols. The importance of Development cannot be over emphasized. Our ability to raise funds has a direct impact on our ability to fund research, educate a diverse array of communities, and provide support for our families.

Development is not something that comes easy to most folks and invariably requires one to step outside of his or her comfort zone. The following individuals have taken on this challenge and comprise your Development Committee:

**Vice President of Development**
José Morales

**Corporate Sponsorship**
Jeff Larimore
John Maccarone
Deb Reed

**Fund Raising**
Katie Larimore
Tim Miller
Jen Wyman

**Administration**
Christy Greeley
Jenni Sexstone
Jen Wyman

One of the objectives of our committee is to broaden the number of events and families helping to raise funds for our organization. We will be reaching out to individuals that have expressed an interest in sponsoring an event in the coming months. There are a multitude of ways one can become involved and the Development Committee is prepared to assist in the form of planning, execution, and funding. Please consider becoming involved at whatever level you feel most comfortable with.

This is an exciting time for all of us. We are making material contributions across multiple
Development Update (cont.)

dimensions and levels. Please do not hesitate to reach out to me (mobile: 203-722-9292 / e-mail: jtm01@optonline.net) to discuss how you can become involved.

I look forward to partnering with each of you to make material contributions in our pursuit of life-changing breakthroughs for our children.

2013 Fundraising Calendar

<table>
<thead>
<tr>
<th>Date</th>
<th>Type</th>
<th>Event</th>
<th>Honoring</th>
<th>Sponsor</th>
</tr>
</thead>
<tbody>
<tr>
<td>01/23/13</td>
<td>On-Line Auction</td>
<td>Round-up A Cure For Cystinosis</td>
<td>Mason Reed</td>
<td>Deb Reed</td>
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<tr>
<td>01/23/13</td>
<td>On-Going</td>
<td>Cystinosis Awareness Bracelet</td>
<td>Steven Schleuder</td>
<td>Terri Schleuder</td>
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<tr>
<td>02/13/13</td>
<td>Letter Campaign</td>
<td>Schleuder Letter</td>
<td>Steven Schleuder</td>
<td>Terri Schleuder</td>
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<tr>
<td>03/17/13</td>
<td>Letter Campaign</td>
<td>Greeley Birthday Letter</td>
<td>Jack Greeley</td>
<td>Christy Greeley</td>
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<td>04/01/13</td>
<td>Letter Campaign</td>
<td>Morales Graduation Letter</td>
<td>Christian Morales</td>
<td>José Morales</td>
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<tr>
<td>04/27/13</td>
<td>Fun Run</td>
<td>Costume Crazies Fun Run/Walk</td>
<td>Mason Reed</td>
<td>Deb Reed</td>
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<tr>
<td>04/30/13</td>
<td>Letter Campaign</td>
<td>Sarah Larimore Conference Fundraiser &amp; 8th Birthday Celebration Letter</td>
<td>Sarah Larimore</td>
<td>Katie Larimore</td>
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<tr>
<td>05/01/13</td>
<td>Fun Run</td>
<td>Wyman 5K Run</td>
<td>Kacy Wyman</td>
<td>Jen Wyman</td>
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<tr>
<td>05/31/13</td>
<td>TBD</td>
<td>Students with Tender Touch For CRN</td>
<td>Laura Krummenacker</td>
<td>MaryBeth Krummenacker</td>
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<tr>
<td>06/08/13</td>
<td>Golf Tournament</td>
<td>C.H. Robinson Golf Tournament</td>
<td>Tahnie Woodward</td>
<td>Tim Miller</td>
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<tr>
<td>06/30/13</td>
<td>Letter Campaign</td>
<td>Josie Sexstone BD Letter</td>
<td>Josie Sexstone</td>
<td>Jenni Sexstone</td>
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<tr>
<td>07/31/13</td>
<td>Fun Run</td>
<td>Muir For A Cure (Hiking the 212-mile John Muir Trail)</td>
<td>Jessica Jondle</td>
<td>Wayne &amp; Jessica Jondle</td>
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<tr>
<td>09/21/13</td>
<td>Golf Tournament</td>
<td>Swings For Sarah Golf Tournament</td>
<td>Sarah Larimore</td>
<td>Jeff Larimore</td>
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<tr>
<td>09/30/13</td>
<td>Multiple Events</td>
<td>Village Club of Lincolnshire</td>
<td>Jack Greeley</td>
<td>Christy Greeley</td>
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<tr>
<td>10/31/13</td>
<td>Fun Run</td>
<td>Zumba For CRN</td>
<td>Laura Krummenacker</td>
<td>MaryBeth Krummenacker</td>
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<tr>
<td>11/30/13</td>
<td>Letter Campaign</td>
<td>Laura’s Letter</td>
<td>Laura Krummenacker</td>
<td>MaryBeth Krummenacker</td>
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</table>
Feature: Megan Hampton
by Megan Hampton

On March 27, 2006, I was 20 years old and had my first transplant. I was scared to death about the whole situation. I didn’t really understand what a transplant meant. I only knew that it would prolong my life. I was very fortunate to not have to go on dialysis. I had several family members come forward and only one was a perfect match, which was my cousin. Unfortunately, I had complications from day one of the transplant. The complications had to do with the ureter narrowing and not allowing urine to go through. I was in and out of the hospital a lot until they put in a percutaneous nephrostomy tube to help open up the ureter and drain the urine. Eventually though I would go through another hardship.

I would find out June 17, 2011 that I was in chronic rejection—the words no one ever wants to hear. I was at first very hesitant to go through another transplant because of all the trouble I had with the first one. I was fortunate to have a doctor who cared so much about me and said she would be by my side and that there wouldn’t be any complications. So, I went ahead and said I would when the time came to get another transplant when my kidney function was low enough.

On July 28, 2012, I was fighting for my life. I felt tired but I just thought it was from overdoing it with my kidney function being low. Little did I know when I went to E.R. that I would be told that my kidney function was 4% with a creatinine of 12.8 and that I would have to start dialysis immediately. I definitely was shocked. I never wanted to do dialysis. However, I knew I would have to until I got a donor. I had a few family members come forward this time. Some of them were not matches but I had my cousin that donated the first time ask me if her cousin on her side could get tested. She did and ended up being a perfect match. So, after several tests and three months later, I had my second kidney transplant.

On October 3, 2012, my second kidney transplant was performed. I knew once I woke up from surgery that this one was different. My nurse came out and said the kidney was beautiful and was working great. From day one I have felt so good. I got up and walked the next day. My kidney function has never been better. I am running now with a creatinine of .5-.6. I have so much energy with this transplant. I sometimes go insane because I am so bored. The only down side about any transplant is the many blood draws. I went from once a month and now twice a week for a while.

I am now volunteering two days a week, which helps keep me busy. I eventually want to look for a job as a Medical Receptionist. I pray that the cure for cystinosis is near and the younger generation will not need a transplant.
Cystinosis and CRN Featured on The Balancing Act on Lifetime Television Series, “Behind the Mystery: Rare and Genetic Diseases,” April 9 and 16, 2013

by Christy Greeley—Executive Director

“Behind the Mystery: Rare and Genetic Diseases” on The Balancing Act on Lifetime Television, is a series produced with the intention of introducing and unifying patient, physician, and scientists with research, education and the opportunity to revolutionize the way our health care system works for those with rare and genetic diseases. The Balancing Act supports and celebrates patient advocacy groups and industry leaders, who inspire connect and guide patients as they move forward through their journey towards treatments and a cure.

Cystinosis and The Cystinosis Research Network (www.cystinosis.org) were featured as part of the series in a segment entitled, “Cystinosis: Courage in the Face of Adversity” on April 9 and 16, 2013. The piece featured expert information on the diagnosis and treatment of cystinosis by Cystinosis Research Network Scientific Review Board member Dr. Craig Langman, as well as the personal story of one family’s experience with the disease which featured mom Jen and Kacy Wyman, age 10, who has cystinosis. The segment can be found via this link: www.thebalancingact.com/video/?v=YHHLC5UHU04525 as well as on the CRN website.

The Balancing Act® on Lifetime Television
Now in its 5th year, The Balancing Act® continues to empower women in all aspects of their lives. The mission at The Balancing Act® is simple. The show strives to help today’s modern woman balance it all by bringing them exceptional solutions to everyday problems. Entertaining, educational and trusted by women, America’s premier morning show The Balancing Act® airs weekday mornings on Lifetime television at 7 am (ET/PT).

For more information please contact us at: www.TheBalancingAct.com
Like us on Facebook at: www.facebook.com/TheBalancingActFans
Follow us on Twitter at: twitter.com/#!/balancingacttv
Or watch us on YouTube at: www.youtube.com/thebalancingact
The 7th annual Cystinosis Charity Golf Event will be held on June 8th at the Thanksgiving Point golf course in Lehi, Utah. (See the official 2013 brochure, below and opposite.)
This year I have a goal of raising $100,000 and I'll need all the help I can get with raising money and obtaining donation items for our raffle. Your personal contributions, corporate matches, and office donations are much appreciated. Thank you for considering supporting our event!

To make a personal donation, go to [http://www.cystinosis.org/donate](http://www.cystinosis.org/donate) and reference the C.H. Robinson event.
My brother Mark had cystinosis. He was diagnosed when he was in the sixth grade. If my memory is right, this was back in 1972. My dad gave him a kidney and he had no problems. Doctors told us how rare this disease was and that he would probably live only until he was 18 years old. At that time, he was the second oldest person in the United States with cystinosis.

Mark and a parent would go to National Institutes of Health (NIH) yearly for testing and trials. While in his early 20s, his eyes started forming crystals, and he eventually went totally blind by age 30. The NIH at that time was just developing drops to help prevent these crystals from forming or dissolve ones already formed, but for Mark this was too late. He passed away in 2003 from what we believe was a stroke. He showed all signs of stroke, but who knows if it was that or if these crystals attacked another part of his body. No autopsy was done. We were blessed to have him until he was 42 years old, and not the 18 years old that doctors had predicted. His transplanted kidney still functioned perfectly all those years. He did have many visits to the dermatologist for years to remove skin cancer from all parts of his body, mainly his face, hands, and arms. He was extremely sensitive to sunlight and always wore sunscreen SPF50, long sleeves, and hats whenever outside. He was an avid gardener and his garden was amazing—way better than even a sighted person’s! Doctors said his skin cancer was most likely effects from post-transplant medications—prednisone and Imuran.

It is so rare to even hear of cystinosis. I hope and pray the research for cystinosis has greatly improved over the years and that individuals with cystinosis can have normal, productive, and very long lives. Prayers are with you all!
NORD Gala to Honor Dr. Jess Thoene and Sigma Tau Pharmaceuticals

The annual National Organization for Rare Disorders (NORD) Gala will be held on May 14th in Washington, D.C. and will celebrate the organization's 30 years of service to the rare disease community. We are proud to attend and support this event.

Sigma Tau Pharmaceuticals will be honored for their approval of the Cystaran eye drops. CRN and NORD Board Member Marybeth Krummenacker will present the award to Sigma Tau on behalf of NORD. Marybeth has great perspective on the long trail to approval of the eye drops as her daughter Laura was involved in the original NIH trial.

Dr. Jess Thoene will also be honored for his leadership on behalf of patients. He has not only been an extraordinary researcher, advocate, and caregiver for cystinosis patients for decades, but has also been deeply involved in the greater rare disease research community, at one time serving on NORD’s Board and working with the organization on the Orphan Drug Act Legislation.

We will attend the event with great pride knowing that these two awards will recognize an individual and a company that have generously supported the cystinosis community over the years. Congratulations to Dr. Theone and Sigma Tau!

The Village Club is Proud to Support Cystinosis Research Network

The Village Club is pleased to announce it has chosen Cystinosis Research Network as its philanthropy for the next two years and is eager to begin fund raising efforts.

The Village Club is a women’s social and philanthropic organization with 200 members, who reside in the Lincolnshire area, a northern suburb of Chicago. The club’s mission is to provide social opportunities for their members, welcome women to the community, and raise money and awareness of a chosen charity.

Most recently, The Village Club’s philanthropic efforts supported The Myelin Repair Foundation raising $20,000 through various events—Photos for Philanthropy, Murder Mystery Dinner, Body Works Spa Night, Salsa Funk to End MS—raffles and member donations. The Myelin Repair Foundation is the world’s largest non-profit research organization exclusively focused on developing the next generation of multiple sclerosis treatment, myelin repair.

Every two years, the Village Club Board of Directors votes to support a new charity. As Christy Greeley, CRN Executive Director is a long-time Lincolnshire resident and past president of the VC, the group is proud to support one from their own community. As these women know Christy and her son Jack, and see the impact of this disease, they are passionate in their support for CRN.
Family Conference
Sponsorship Opportunities

CRN is pleased to announce that the 2013 Family Conference will be held July 18-20, 2013 at the Marriott Wardman Park Resort in Washington, D.C. This will be CRN's sixth family conference.

We cordially invite you to take advantage of the great sponsorship opportunities available to not only celebrate the remarkable accomplishments of the Cystinosis Research Network, but to support the vision of CRN: The discovery of improved treatments and ultimately a cure for cystinosis. Our commitment to our community lies in our tireless efforts to provide family assistance through facilitating several support groups as well as hosting a biennial conference. At this conference we bring families and the medical community together in hopes to accelerate the accomplishment of our stated goals and objectives.

Past sponsors include:

**CRN SPONSORSHIP LEVELS**

**Platinum Event Sponsor $30,000**
- Dinner invitation to board and medical advisory meeting/dinner
- Premium placements in donor banner displayed at conference
- Verbal recognition at the conference opening
- Verbal recognition at the cocktail reception
- 11x17 laminated color poster placed at the event
- Logo on website with direct link to donor
- Logo and/or advertisement in pre-conference newsletters
- Included in email blasts and all conference related announcements and materials (time permitting)
- Top Logo representation on conference t-shirt
- Donor literature included in each guest room
**Silver Event Sponsor $15,000**
- Dinner invitation to board and medical advisory dinner
- Verbal recognition at the conference opening
- Verbal recognition at the cocktail reception
- 11x17 laminated color poster placed at the event
- Logo on website with direct link to donor
- Logo in pre-conference newsletters
- Included in email blasts and all conference related materials (time permitting)
- Logo representation on conference t-shirt
- Placement in donor banner displayed at the event

**Bronze Event Sponsor $10,000**
- Verbal recognition at opening reception
- Verbal recognition at cocktail reception
- 11x17 laminated color poster placed at the event
- Logo on website with direct link to donor
- Logo in pre-conference newsletters
- Included in email blasts and all conference related materials (time permitting)
- Logo representation on conference t-shirt
- Placement in donor banner displayed at the event

**Breakfast Sponsor $3000**
- Recognition at conference opening
- 11x17 laminated color poster placed at each day’s breakfast
- Placement in donor banner displayed at event
- Included in all the event’s email announcements
- Logo on the website with direct link to donor

**Lunch Sponsor $3000**
- Recognition at conference opening
- 11x17 laminated color poster placed at each day’s breakfast
- Placement in donor banner displayed at event
- Included in all the event’s email announcements
- Logo on website with direct link to donor

**Napkin Sponsor $1000**
- Donor's logo printed on cocktail napkins displayed at the cocktail reception
- Placement in donor banner displayed at event
- Included in all the event's email announcements
- Logo on website with direct link to donor

**Registration Table Sponsor $1000**
- 11x17 laminated color poster placed at the registration table
- Placement in donor banner displayed at the event
- Included in all the events email announcements
- Logo on website with direct link to donor

**Inspirational Speaker Sponsor $500**

**Cocktail Reception Sponsor $500**

**Conference Materials Sponsor $500**

**Childcare Sponsor $500**

**Closing Dinner Sponsor $500**
Join 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 Cystinosis Research Network is a volunteer, non-profit organization dedicated to advocating and providing financial support for research, providing family assistance and educating the public and medical communities about cystinosis. 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:

“Dedicated to a Cure. Committed to our Community”...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 biannual CRN Newsletter, our very informative web page www.cystinosis.org, the 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.
- 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 Cystinosis Research Network today!

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

Pam Woodward
VP Family Support, Cystinosis Research Network
Join the Cystinosis Research Network Today!

<table>
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<tr>
<th>Category</th>
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<td>Immediate Family</td>
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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:
Cystinosis Research Network
302 Whytegate Ct.
Lake Forest, IL 60045

*****************************************************************************
Name_________________________________________________________________________
Street________________________________________________________________________
City & State_______________________________________ Zip Code__________ Country ____
Phone__________________________Fax_______________________Email________________
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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 two 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.
# 2012 Donor Honor Roll

## Over $50,000
- Raptor Pharmaceutical Corp.

## $25,000–$50,000
- C.H. Robinson
- Cystinosis Foundation Ireland

## $10,000–$24,999
- Cynthia Gray
- Dorsey & Whitney Trust Company LLC
- Sigma-Tau Pharmaceuticals, Inc.

## $2,500–$9,999
- Don L. Schleuder
- Goldman, Sachs & Co Matching Gift Program
- Horrigan Family
- Jack & Colleen Hammond
- Jeanne Oki
- Long Island Charities Foundation Inc.
- Network for Good
- Philip Wales
- Roberta Hancock
- Roller Skating with Rickets
- Special Kids Network, Inc.
- United Way of NYC

## $1,000–$2,499
- Alana Moehlman
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- Branch Banking & Trust Co.
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- Triple Crown Sports Memorabilia, Inc.
- United Way–AT&T Giving Campaign
- United Way–Metro Atlanta
- United Way–Metropolitan Chicago

## $500–$999
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United Way of Michigan
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William Murphy
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Mike & Fran Krummenacker
Mike & Janae Schumacher
Mike & Tracy Fillion
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<tr>
<th>Name</th>
<th>Name</th>
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<tr>
<td>Mr. &amp; Mrs Mark Ogan</td>
<td>Sarah &amp; Gary Cohen</td>
</tr>
<tr>
<td>Nancy Boland</td>
<td>Scott E. Skrynecki</td>
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<td>Nancy Davis</td>
<td>Sharon A. Farnsworth</td>
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<td>Nancy Haddad</td>
<td>Sherie &amp; Randy Eschels</td>
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<td>Nancy J. Gifford</td>
<td>Shirley M. Darbee</td>
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<td>Nancy M. &amp; Howard S. Baron</td>
<td>Solid Craft Cabinetry LLC</td>
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<td>Southern Realty Development Corp.</td>
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<td>Neil B. &amp; Judy D. Cohen</td>
<td>Stacey &amp; John Paolello</td>
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<td>Stacy A. &amp; Steve A. Church</td>
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<td>Stanley &amp; Ilene Burmood</td>
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<td>Patricia &amp; Edward Olsson</td>
<td>Stephen J. &amp; Jillian Nazzaro Jr.</td>
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<td>Patricia Jette</td>
<td>Stephen J. Minns, DDS</td>
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<td>Patricia Motes</td>
<td>Steve &amp; Anne Wolf</td>
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<td>Susan &amp; Brian Roberts</td>
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<td>Paul &amp; Michelle Cavazos</td>
<td>Susan &amp; Thomas Schendel</td>
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<td>Paul A. &amp; Theresa L. Magro</td>
<td>Susan E. Neumann Gorzynski</td>
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<td>Peter D. &amp; Bernadette Costas</td>
<td>Susan Mateika</td>
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<td>Philip Appel</td>
<td>Suzann &amp; Michael Neff</td>
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<td>Phyllis Radcliff</td>
<td>Tara Finke</td>
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<td>RMR IV</td>
<td>Tara M. &amp; Tom W. Atkinson</td>
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<td>Raymond Mellon</td>
<td>Ted &amp; Kim Forrester</td>
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<td>Renee Judycki</td>
<td>Ted Duncan</td>
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<td>Renee M. &amp; Anthony Greco</td>
<td>Terri Jones</td>
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<td>Richard &amp; Judith Bagdon</td>
<td>Terry F. Zerlak</td>
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<td>Richard Capewell</td>
<td>The Earl &amp; Bettie Fields Automotive</td>
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<td>Richardson Seeds, Ltd.</td>
<td>Theresa McNiff</td>
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<td>Robb Allen</td>
<td>Thomas &amp; Carol Bowen</td>
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<td>Robert &amp; Kelly Kirkman</td>
<td>Thomas &amp; Lisa MackIllop</td>
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<td>Robert J. &amp; Cindy Kondzielaski</td>
<td>Thomas B. &amp; Laura Reed</td>
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<td>Roberts Food Service, Inc.</td>
<td>Thomas H. &amp; Brenda K. Phlipot</td>
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<td>Ronld K &amp; Jody Weiss</td>
<td>Thomas Lyons</td>
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<td>Rosyln Bernstein &amp; Peter J. Mannon</td>
<td>Thomas M. &amp; Cindy J. Propps</td>
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<td>Russell &amp; Elise Bratley</td>
<td>Thomas Schultz</td>
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<td>Salvatore Golisano</td>
<td>Tim W. &amp; Mary Winter Teaster</td>
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<td>Sandra &amp; George Pyrz</td>
<td>Timothy &amp; Carrie Celovsky</td>
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<td>Sandra B. &amp; Richard H. Simon</td>
<td>Timothy &amp; Catherine Klie</td>
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<td>Sandra Roberti</td>
<td>Timothy McKeown &amp; Mary C. Resing</td>
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Todd & Diane Gillis
Todd & Julia Wells
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Trent Ledford
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In Honor Of_____________________________________________________________

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

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

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Cystinosis is a rare disease that primarily affects children. Cystinosis is a genetic metabolic disease that causes an amino acid, cystine, to accumulate in various organs of the body. Cystine crystals accumulate in the kidneys, eyes, liver, muscles, pancreas, brain and white blood cells. Without specific treatment, children with cystinosis develop end stage kidney failure at approximately age nine.

**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 (CRN) is a volunteer, non-profit organization dedicated to advocating and providing financial support for research, providing family assistance and educating the public and medical communities about cystinosis.