An Evening of Laughter, a Wonderful Success for CRN

By: José T. Morales

The event was An Evening of Laughter, a fundraiser conducted on behalf of The Cystinosis Research Network. The venue, the stately and beautiful Carlyle On The Green located at Bethpage State Park, NY. The principle CRN hosts, the Maccarone Family. Partnering with John and Arlene were CRN members: Marybeth Krummenacker, Christy Greeley and José Morales. The evening was in a word Magical. Magical from the very beginning to the very end. There was much anticipation as the evening hour for the event to begin; and then, before you knew it, the hallways and rooms were filled with smiling faces, laughter and conversations. Colleagues, friends and family convened to celebrate life and work towards supporting CRN, an organization with a full scope of aspirations: everything from sponsoring research, to promoting education and awareness amongst its community and medical providers, to supporting families during periods of critical need.

Downtown Chicago, site of 2015 CRN conference

Downtown Chicago, site of 2015 CRN conference

2015 CRN Family Conference Planned for July 16th-18th in Chicago

The Cystinosis Research Network is pleased to announce that its 2015 Family Conference will be held July 16th – 18th at the DoubleTree by Hilton Chicago-Magnificent Mile.

Please save the date, mark your calendars and plan to join us. It is a great opportunity to reconnect and learn more about new research findings, receive updates from cystinosis organizations from

(continuation on page 39)
The President’s Letter

A Commitment to Community

By Jeff Larimore

When the charge of writing the President’s letter for the Spring & Fall editions of the Cystinosis Advocate arises, I try to envision what remarks I can make to the Cystinosis community that may cause an action or at least commence a conversation. My opening remarks for the Fall 2014 edition of the Cystinosis Advocate is a rather personal statement – “I really enjoy the opportunity to be President of the Cystinosis Research Network!” It is inspiring to work closely with a team of caring individuals and families that represents the membership of CRN and to engage directly with committed health care professionals who each day strive to improve the quality of life for our young and “getting older” children. These interactions drive CRN’s ongoing Commitment to the Cystinosis Community.

Throughout 2014, the CRN membership has blazed forward to accomplish the areas of concentration presented about a year ago. Key objectives achieved were:

- Broadening communication within the Cystinosis community to inform patients and caregivers of the personal and medical resources on the CRN website,
- Present education forums where current medical and patient developments are openly discussed – six forums have been held in 2014 and others will be announced for early 2015,
- A dramatic increase in Fundraising events during 2014 provides CRN with a solid balance sheet,
- An expansion of the awareness and education of Cystinosis to improve the transition to adult care – older individuals managing with Cystinosis have spearheaded progress in this area,
- To continue to inform patients with Cystinosis that volunteer work within the community will pay future dividends. During 2014, nearly 20 young adults have expressed an interest in increasing volunteerism with the Cystinosis Research Network.

The Cystinosis Research Network will continue to strive toward the accomplishment of its vision and mission. During 2015, we will continue to provide research grants that progress toward new breakthroughs in managing the current and future effects of Cystinosis. We will continue forward in working with dedicated pharmaceutical companies and dynamic researchers who focus on pioneering new treatments for the betterment of the lives of those within our Cystinosis families. In addition, there will be a continuation of effort to improve the quality of lives and the management of care for our community.
Initiatives being formalized by the Cystinosis Research Network will look to those with Cystinosis to “raise their game” and get into the mix of the conversation. We have frequently discussed areas of transition throughout this community and often identify the difficulties and challenges associated with change. The Cystinosis Research Network prides itself on its openness and broad outreach to the entire Cystinosis community. Time continues to move in the direction where the Cystinosis Research Network transforms to a true “patient” advocacy organization.

CRN’s Commitment to Community will expand dialogue and develop action plans that seek direct engagement from those with Cystinosis. Our committees are targeting programs that develop a “mentoring” environment from within so that engaged individuals can develop team building and leadership skills. The output of these engagements would provide a wider skill set which can lead to potentially improved professional opportunities. Other mentoring engagements would be designed to develop long and life-time relationships with peer-to-peer or big & little communication through social media outlets or pen pal circles.

CRN will also concentrate on improving the distribution of medical information regarding Cystinosis. It is becoming too frequent where those with Cystinosis who are making the commitment to self-monitor and manage their health care are becoming frustrated with the hurdles of inconsistent medical advice. In addition, one fewer day of a lack of diagnosis or misdiagnosis of Cystinosis gives families an opportunity to start on a course of action and possibly one fewer sleepness night. We will continue to streamline to the medical community the abundance of medical resources in place regarding Cystinosis via the CRN website (www.cystinosis.org). In addition, we will continue to strengthen our direct lines of communication with university-based medical centers along with urban and rural hospital systems.

The members of the Cystinosis Research Network are proud of the progress in advocacy for those with Cystinosis. It remains a priority to be the standard bearer for the Cystinosis community.

With the near conclusion of another dynamic year and with the inspiration that drives us into the future, we are truly appreciative of your continued support. On behalf of the Board of Directors of the Cystinosis Research Network, all the best wishes for this holiday season.
CRN Welcomes three New Board Members

The Cystinosis Research Network is pleased to announce the election of three new Board members, Clinton Moore, Ina Gardener, and Katie Morrison. We also sincerely thank retiring Board members, Britney LeBeau, Jen Wyman and Kathy Mullen for their many years of service to CRN. Each new Board member will introduce themselves below.

Hello Everyone, my name is Clinton Moore. I am happily married to Annie Moore and we have one child named Chandler. We live in a small town called Georgetown, Delaware. I have been in the masonry trade for 18 years and have been a masonry contractor for the past 14 years.

Cystinosis came into our lives when Chandler was just ten months old. He is now 9. We have worked hard everyday to make sure that cystinosis does not define who he is or limit what he can do. We have also been very dedicated in trying to raise spirits and create a strong, fighting attitude within the cystinosis community through social media. Our commitment will continue every day until a cure for cystinosis is found.

My name is Ina Gardener and I was born in Muskogee, Oklahoma, but have lived in Ohio the majority of my life. I am married to Victor Gardener, Sr. and we are proud parents to two wonderful children named India and Victor, Jr. I have a Bachelor’s Degree in Psychology and am presently pursuing a Master’s Degree in Clinical Counseling. I have been a Dialysis Tech. for the past 20 years and have worked with adults and children afflicted with kidney disease. My son Victor is 14 years old and has cystinosis. Unfortunately Victor did not receive his diagnosis until the age of 4. Through the four years of not knowing, I want to believe that an Angel was watching over Victor and directing us to the path we needed to be on. I also believe that GOD led me into my present profession because He knew that one day I was going to need to know, understand and be prepared for the road to come.
My name is Katherine Morrison, I was born and raised in Memphis, Tennessee. I have three other siblings, myself being the only one with cystinosis. As a person living with a rare genetic disease I take every day as a gift and appreciate the small things. I received a kidney transplant when I was eight, a week before Thanksgiving, and have not looked back since. I am very fortunate to have had a very successful transplant and a very supportive family. Despite having cystinosis there have been other adverse things that have come my way. My parents divorced when I was five and lived at different ends of the city. When I was nine my mother moved to Florida and has lived there ever since. So I grew up with a separated family, a parent living in a completely different state and a rare medical condition. These are not reasons to pity a person, but it is reason for a person to be driven, strive to do her best, and embrace life.

I am about to graduate college and hopefully pursue a career as a Registered Dietitian. I am more grateful than ever for the people who raised me and for the health I have today, allowing me to achieve my dreams. To play a larger role in the Cystinosis Community would be an amazing opportunity. It would give me the chance to reach out to others with cystinosis and encourage them to live life to the fullest. By being involved, I hope it will encourage others to be involved as well. I want to set an example of community support and encouragement for others, whether or not they have medical issues. People will find happiness by embracing life and helping others, rather than letting negative issues take control of their lives. This is the message I want to send by being involved in the cystinosis Community.

2014 CRN Scholarship Recipients Named

By Terri Schleuder

The Scholarship committee is pleased to announce the winners of our two 2014 CRN Scholarships. This year we did not receive any applications for our Individual with Cystinosis Scholarship so we awarded two Sierra Woodward sibling scholarships. One to Caroline Larimore, who will study at the University of South Carolina and another to Jack Wyman, who will attend Albion College in Albion, Michigan. Congratulations to both of these exceptional young people as they pursue their educational goals.

I am honored to receive the CRN sibling scholarship that will go toward my education at Albion. It is going to help me be able to study at a high quality school, play baseball, and be close (enough) to home. Thank you!

Jack Wyman and his sister Kacy

(Cont. on page 6)
Hi everyone! I am extremely honored to be the recipient of one of the two 2014 Sierra Woodward Sibling Academic Scholarships! I was informed of the award right before one of my classes began, and at that moment I knew I chose the right place to continue my education! I am a freshman at the University of South Carolina with a double major of Global Supply Chain and Operations Management and Marketing at the Darla Moore School of Business. I also declared a minor in French. With the help of this scholarship, I can reduce the cost of tuition and focus less on student debt and more on achieving my goals of studying abroad in France and graduating with a secured job in four years or less. The Cystinosis Research Network has given an immense amount of support to my family and I am proud to represent both my family and my Cystinosis family at South Carolina as I work to earn my degree and continue to make a positive impact in the Cystinosis community. Go Gamecocks!

The Midwest Cystinosis Family Gathering Celebrates 25th Year Anniversary

By Joan Hohl

The weekend of July 18th-20th, marked the 25th year our Midwest Cystinosis Family has gathered for a weekend of sharing, eating, and enjoying time together. What started as a conversation in 1989 at the NIH (National Institutes of Health) became a reality during the summer of 1990 at Big Lake State Park near Bigelow, Missouri. We have gotten together at numerous locations around the mid-west, rotating the host/hostess among the families—who then choose a location.

This summer we gathered in Cedar Rapids, Iowa with one of the young adults with cystinosis, Andrew Hoffmann age 26, in charge of the weekend.

Andrew started by preparing and setting up a taco bar for us at the motel on Friday night. Saturday, he took us to the downtown Cedar Rapids Farmer’s Market where some purchased fresh produce, and handmade jewelry and soaps.

Andrew planned a grill-out and picnic for Saturday lunch at a nearby park, Lake McBride.
While Andrew played chef; some walked to the lake, others looked at photo albums and talked, and others ‘played bags’ in teams of 2. Saturday evening we attended a local baseball game, where a Minnesota Twins’ farm team, the Cedar Rapids Kernels beat out the Fort Wayne Tincaps. GO Kernels!!

Our weekend was completed with individual family pictures, and a whole group picture with our lime green t-shirts (donor awareness color). The t-shirts were designed by David Reuter, who has cystinosis and is completing an Art Degree; and are dedicated to 25 years of ‘family gatherings’ and memories of ‘family members’ who are no longer with us. The front logo is repeated on the back.

Included in the group picture: back row, left to right: Ryan Farnsworth, Blake & Khristy Rollinger, Allie Norris, Jon Hoffmann, Amy Rollinger, Sarah Rich, Joan Hohl, Doretta & Don Hoffmann, Kasey & Lonnie Hohl, Holly Reuter, Candy & Don Wagner.

Front row left to right: Bill Croce, Sarah Farnsworth, Andrew Hoffmann, David & Shawn Reuter, and Nick Wagner.
Evening of Laughter (cont. from page 1)

It is not possible to conduct an event of this scale alone. Individuals committed to making a difference and helping fight this rare disorder surrounded John and Arlene:

"To whomever much is given, of him will much be required; and to whom much was entrusted, of him more will be asked."

Luke 12:34-48

John and Arlene's friends rallied and joined the Planning Committee and were "all in" from the very start:

**Evening Hosts**
- John & Arlene Maccarone - Maccarone Plumbing Inc.
- José & Velyna Morales - fM Fashion and Music LLC
- Peter & Elen Pavlakis - PavLak Contracting Inc.
- Peter & Karen Ferrandino - Ferrandino & Son Contracting
- Albert & Fran Paniccia - Casa Building Supply
- Marybeth Krummenacker - CRN Board Member
- Christy Greeley - CRN Executive Director & V.P. of Research
- Emmett & Karen Laffey - Laffey Fine Homes

The evening's program was ambitious:

**Welcome Reception**

**Silent Auction**

**2014 Above and Beyond Award - Dr. Frederick J. Kaskel**

**Key Note Speaker - Dr. Marla Friedman**

**Personal Testimony - Johnny Maccarone**

**Live Auction - Auctioneer Gianni Russo**

**Entertainment - Kevin Pollik**

**After Party**

It is hard to capture in words the feelings and emotions experienced throughout the night. Perhaps by sharing a few highlights we might be able to convey how special the evening was:

**2014 Above and Beyond Award - Dr. Kaskel was very gracious in accepting the**
2014 Above and Beyond award. Dr. Kaskel emphasized the critical role patient advocacy organizations play in promoting research and treatment for rare diseases. Dr. Kaskel recognized CRN as a leading patient advocacy organization worthy of emulation.

**Key Note Speaker** - Dr. Marla Freidman’s address emphasized the importance of having holistic awareness of one's body, mind and soul. The ability of an individual to see things about ourselves that we may have been unaware of and to use these new insights constructively. Empowering us to build healthier relationships with ourselves and others with the goal of integrating past with present, and living a healthier, more abundant and balanced life. Dr. Freidman’s insights resonated with everyone in attendance.

**Personal Testimony** - Johnny Maccarone addressed the audience, sharing how he finally came to be aware of the fact he and his brother, Brandon, had a rare disease and how fortunate they were to have such a strong family circle that is ever so vigilant. In addition to thanking his Mom and Dad, Johnny recognized his maternal grandparents, Jack and Arlene Sheridan, for their unconditional love and constant support. Johnny asked everyone to help the children coping with cystinosis to have better lives.

**Live Auction** – Gianni Russo orchestrated the high-spirited live auction. Gianni starred in the greatest movie of all time, "The Godfather", as Carlo Rizzi, Don Corleone’s wife-beating/double-crossing son-in-law. Gianni has since starred in over 40 movies during his career. Gianni used his unique style to engage folks in bidding for a multitude of auction items.

**Entertainment** - The evening’s entertainment was a very special treat, Kevin Pollak. An award-winning actor with over 70 films to his credit, including *A Few Good Men*, *The Usual Suspects*, *Casino* and *Grumpy Old Men*. A gifted comedian, who Comedy Central named "One of the Top 100 Comedians Of All Time.” Kevin regaled the audience with stories from his films. Sharing stories and impersonations of his famous co-actors: Jack Nicholson, Walter Matthau, Robert DeNiro, Martin Scorsese and many others.

**After Party** - After the formal program ended, participants continued the evenings celebration by dancing late into the night to music provided by DJ Nester. Some of the folks indulged in an after-dinner drink and a cigar on the patio to warm the belly and put a finishing touch to a magical evening.

Such an undertaking would not be possible without having significant support and sponsorship. The following individuals and companies are recognized for their support.

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Keynote Speaker, Dr. Marla Friedman

2014 Above and Beyond Award winner, Dr. Rick Kaskel with Arlene Maccarone

José & Velyna Morales enjoy the evening

(Cont. on page 12)
An Evening of Laughter Enjoyed By All!
Evening of Laughter (cont. from page 8)

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- Susan Picardi
- Gianni Russo
- Joanne VonZwel
- Father Daniel

Kristen Balsour and Ashley Newmark welcome guests to "An Evening of Laughter"
Folks continued to celebrate and enjoy the evening until the final song was played around midnight. The Planning Committee was “present and accounted for” as the final goodnights and goodbyes were exchanged.

A magical evening, magical friends and magical accomplishments made possible by people inspired to make a difference. Over $325,000 was raised during the evening on behalf of CRN. CRN is committed to using these funds towards achieving its vision and mission.

A heartfelt “gracias” to all of you that contributed individually and collectively to making this possible.

Do you want to connect with cystinosis families in YOUR area?

Visit http://www.cystinosis.org/families-in-your-area. Send your contact info to the e-mail listed to learn who is in your area. It’s that easy!
Five Tips for Living with Cystinosis

(Editors note: This article originally appeared in Tahnie’s wonderful Blog, A Happy Girl. To read more of her inspiring entries check out her Blog at this link: www.ahappygirl.com)

By Tahnie Woodward

I’ve been wanting to write a post like this for quite some time. The cystinosis community is small, albeit mighty. I’m endlessly grateful for the ways people in our little family support each other. Insecurity kept getting in the way of me publishing this piece, because I definitely don’t have it all figured out. I finally decided to go for it though. I’ve been living with cystinosis for 31 years now and I’ve learned a few things along the way. Obviously, I am not a doctor but these are some points I believe can help. I’m excited to share them today! (Nerves be done. Ha.) Really, these tips can easily transform to other chronic diseases and health adventures, but I wanted to focus on cystinosis today because resources can be tricky to find due to the rarity of the condition.

1. Remember your journey is yours and your alone.

It doesn't matter where you are in your journey with cystinosis, or who you are. If you are a parent, or a friend, or the person living with it each day, always remember the details of the story are unique to everyone. I think sometimes people can get really caught up in comparing, when a disease is so rare like this one. It truly is crucial to walk your own path. Whatever that may mean to you and your circumstances.

2. Trust your gut instincts.

Confession: there have been many times when I’ve rebelled and not listened to what was recommended. I’m still here to talk about it! An example would be growth hormone injections to assist my body in the growing process. They are quite popular with many people and their cystinosis stories. Personally, I felt confident in my decision to skip them when they were offered to me by my nephrologist. It was a tough health time in my life and I had other priorities. In addition, there was that little gut instinct that I couldn't shake off. I don't mind being 4'11" now either. Wink. As often is the case, we have to choose our battles. I love that we have choices like this.

Tahnie Woodward and her daughter Sookie Boyer
3. **Embrace normalcy.**

This is huge. I’ve never particularly been fond of the word normal anyhow, because I don’t believe anyone knows what that is! The oven timer goes off multiple times a day around here to remind me to do my eye-drops. Sookie is used to it. We all are. It is our normal. This is a miniature example. Really though, create your life the way you were going to anyway. Sure you have to shift some things and make room for extra obstacles, but find your version of normal. Then rock it out of the park and create your wonderful life from the ground up. It is possible.

4. **Do your own research.**

As I covered before, many practices seem like a go to in the cystinosis world. However, I really encourage people to do their own research. Simply because a certain intervention works wonderfully for one person, doesn’t immediately mean it is for you. You have to take into account your whole picture, not the one facet of cystinosis. And my goodness, listen to your body. You know it better than anyone else.

5. **Ginger root is an incredible natural aid for nausea.**

When I became a mom, I took a step back from my medications and made adjustments to natural alternatives. I completely understand this isn’t always feasible, but you may be surprised where it is indeed possible. Nausea is a common side effect of cysteamine and at times it can be absolutely brutal, depending on how your body tolerates the medication. I’ve been off of all acid reducers for over 5 years now and it is such a relief. I started researching the long term side effects of these drugs and it was some eye opening information. I take organic ginger root capsules with every dose of cystagon. You can purchase them from Amazon as well as any health food store.

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**Correction to Nutrition in Cystinosis Article**

Editors note:

It was brought to my attention I had misstated Kelly Rulle’s title in her article that appeared on page 24 of our Spring/Summer 2014 Newsletter. Kelly’s correct title is DTR (Dietetic Technician Registered), not a Dietician as stated in the piece. We regret any inconvenience this may have caused Kelly.
Cystinosis is the best thing that has ever happened to me. I mean that not as a polarizing statement, but as a personal one. I have always enjoyed the gifts cystinosis has lavishly bestowed upon me—even those that come disguised as hardship.

It’s a good thing that I feel this way, because cystinosis is written into my DNA. I can’t just shake it off Taylor-Swift-style. It’s good to avoid hating your DNA, because, well, you’re kind of stuck with what you got. Literally. Unless you get those eye color-changing contact lens. Those are awesome.

But there is no denying that cystinosis can be destructive, and it has cost many people their lives. Too many. That is why the Cystinosis Research Network is so intent on raising funds, building awareness, and bringing families together for support. I am so grateful that such a community exists, and sometimes (OK, a lot of the time) I feel like I don’t show that appreciation or give back enough in return. Maybe it’s a zero-sum game: but I’m still trying.

My husband Wayne and I did a charity hike for CRN in September. This wasn’t something that we planned far in advance; in fact, although hiking the 211-mile John Muir Trail (plus the combined 10 miles it takes to reach it and exit it) had been a dream of mine since I started hiking to combat pulmonary decline in early 2012, it wasn’t something I thought we’d ever be able to schedule logistically.

But a pretty crazy blessing happened in July: I lost my teaching job. The K-8 school where I started teaching in 2005 decided to close its doors to the upper grades and continue as just a K-5, leaving me to continue working at a job that I thought would be for the summer only.

My first thought—before I even stopped to feel sad about the loss—was that without the school year constraints, now I could make the John Muir Trail a reality in September! So I put in a request for two weeks off and Wayne and I got started planning.

We wanted to take the cystinosis community with us on this journey, in part because I only ever took up hiking and considered the John Muir Trail because of cystinosis. (Remember how thankful I am for this beautiful mess of a disease?) I wanted to have my heroes on my heart—so I literally put them on my bag, attaching buttons of individuals with cystinosis to my pack. We dedicated each mile hiked to an individual based...
on a sponsorship price of $20 per mile. Although not every mile of the trail was sponsored, we raised almost $3000 for cystinosis research and had many miles covered.

There were truly moments when I didn’t want to continue. There was even a time when I had to come off the trail due to difficult circumstances and reenter after a few recovery days. I found it hard to eat and the cold almost unbearable. Most of the trail is above 10,000 feet and no section of it until near the end is flat—it is a constant up-and-down over mountain passes. We traveled south-to-north, starting with a hike to the top of Mt. Whitney (the highest point in the contiguous United States) and ending in Yosemite Valley (although a fire closed the final 12 miles of trail).

But those with cystinosis constantly motivated me. I kept aware of what mile we were on and knew who I was hiking for. A landmark would appear in the distance—Guitar Lake or Donahue Pass or Crabtree Meadow or Garnet Lake or any number of other places—and I would think about the individual whose mile it represented. Several hikers asked about the buttons on my pack, the most common question being, “Are those your kids?” (say what?! There were 40 buttons on that pack!), and it gave us a chance to describe cystinosis to a wide variety of strangers.

I wish I could share with you all the thoughts that went through my head as I thought fondly of those for whom each mile was dedicated, but those are not my stories to tell. Needless to say, from those who are on dialysis to those who have recently received kidney transplants and one sweet individual who recently passed away, each and every person inspired me.

Here are some things the John Muir Trail taught me about life, love, and cystinosis:

1. **It won’t be like walking on the moon.**

   One morning we crossed paths with a solo hiker headed the opposite direction and let him know we were headed toward Donahue Pass at 11,000 feet. We were around 9,500 feet at the time.

   “Oh my,” he said. “You have a long way uphill.” He must have seen the melancholy written all over my face for he quickly added, “But it’s like walking on the moon. It’s beautiful up there. Otherworldly.”

   Six hours later, I struggled to experience the moon walk. My pack was still heavy. My body was not weightless. Gravity still tugged at my every muscle, silently pleading, “Sit down.”

   But there is a force greater than gravity, a voice louder than Isaac Newton’s, and that is the voice that says, “Here you are, weight at all.”

   The cystinosis life is not weightless. You cannot put down your heavy pack. But you should carry it. You must carry it. It’s not going anywhere unless you do. And with a little practice, you can carry it with joy.  

(Cont. on page 19)
We discovered these stones leaving Trail Camp and heading toward Mt. Whitney Summit.

We encountered a lightening storm and a couple of overnight freezes.

Johnson Meadows, one of the places we expected to find water to filter, but instead discovered more of a stagnant puddle.
Hike for a Cure (cont. from page 17)

The alternative is to look at your heavy pack, plop yourself down on the couch and refuse to move, and complain about how heavy the pack sitting beside you is and explain to others how it gives you a reason not to move.

2. **You’re always almost somewhere.**

Another day, we passed a hiker who heartily patted me on the shoulder as he was headed down and we were headed up. “You’re almost there,” he said.

*Almost where? I wondered. The audacity of this guy, assuming he knows my journey!*

But we are always almost somewhere. Maybe it’s not always close to where we think our destination is, but we are always near the next landmark of our lives. We become so laser-focused on an important end goal (say, a cure) that we forget that our journeys are varied and complex, brimming with life, and worth experiencing 110%.

3. **The right way is usually the up way.**

Whenever the trail forked, I knew our path was the one that went up. And lo and behold, that was also the path that led to the sweeping mountain passes and overlooks.

I hope the sting of this quote is lessened by the fact that I started hiking due to an unfortunate pulmonary diagnosis that I’ve since managed to turn around. John Muir said, *"Few places in this world are more dangerous than home. Fear not, therefore, to try the mountain passes. They will kill care, save you from deadly apathy, set you free, and call forth every faculty into vigorous, enthusiastic action. Even the sick should try these so-called dangerous passes, because for every unfortunate they kill, they cure a thousand."*

4. **The toughest days are not necessarily the ones with the steepest paths.**

One of the days I most dreaded while preparing for the JMT was Day 2. This day included the summit of the highest mountain in the Lower 48, which necessitated a 99-switchback, 2000-foot climb first thing in the morning.

I built this challenge up in my mind, but in the end, it wasn’t the one that took me down. It was the steepest path I had to walk, but I was also ready and on my guard.
It was Day 3, a day I had predetermined as “easy,” that I really struggled. An unexpected storm brought freezing cold and treacherous lightning. The altitude I had quickly attained robbed me of my appetite. And a single mile dragged on for hours.

We don’t often anticipate the tough (unless you anticipate every day to be an upcoming battle—which, to be honest, I don’t recommend).

5. **If you did it yesterday, you can do it today. If you do it today, you can do it tomorrow. Kind of.**

Obviously, this argument is fundamentally flawed; if it were true, we could live forever. But the idea behind this one is that you need to keep going, being ever diligent (while not seeing it as survival or a battle or work) as you live this life. Building off #4, you have to take care of yourself in order to continue on the trail day after day.

6. **Hike your own hike.**

This is a popular mantra among hikers, backpackers, and peak baggers. In a nutshell, there is a lot of advice out there as to how to complete a thru-hike like the John Muir Trail. But it may not all fit your unique circumstances. Similarly with cystinosis—make your experience your own while never refusing to accept or give supportive words to others who may be experiencing things quite differently.
7. **Love the one you’re with.**

This is your life. You can’t trade it. Love it for all it contains. This is a lesson that I learned (or rather, realized again) before I even hit the trail. We aren’t given many years on this planet, and losing a job reminded me of how much stuff there is to do in not-so-much time. How fortunate to be able to explore one more thing because of a circumstance others may see as unfavorable. How can I view cystinosis as unfavorable when it has propelled me to these adventures that afford me such tremendous views of creation?

On a more personal side, my love for Wayne only grew during the challenges of this experience. Not only did he carry our communal gear, but he also set up the tent each night and cooked the food. He was and is a huge support in everything, and I couldn’t be more grateful. He has humored me up Mt. Kilimanjaro in Africa, motivated me on the John Muir Trail, and encouraged me to challenge what it means to have cystinosis.

We are all hiking a life trail every single day. There are mountains to summit and valleys to cross. I hope that the trail is smooth and glorious for every single one of you in the cystinosis community. But if that’s not possible, I hope it’s challenging and glorious.

We want to thank everyone who came on this journey with us and sponsored a mile and/or sent a picture of themselves or their child. It means the world to me. We are on this journey together. Thanks!

“In this life we are all just walking up the mountain and we can sing as we climb or we can complain about our sore feet. Whichever we choose, we still gotta do the hike. I decided a long time ago singing made a lot more sense.” –Unknown

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**AAP Conference Held in San Diego Oct. 10th –13th**

**By Terri Schleuder**

It was a beautiful autumn day, and though I was excited to be headed to sunny San Diego, to represent CRN at the American Academy of Pediatrics Conference held there Oct. 10-13, I was dreading the 4 ½ hour flight to get there from Detroit. I’d brought enough reading materials along, but pleasantly didn’t even look at page one!

The two women seated in my row, I learned, were pediatricians headed to the same conference. We talked and shared stories as we learned about each other during the flight. In no time at all we were landing in San Diego. It was one of the most pleasant flights I’d ever taken.

(Cont. on page 23)
Finance Update

By Jeff Larimore

The Cystinosis Research Network, Inc

Financial Review – Accrual Basis

For the 9 months ended September 30, 2014

Revenues

For the nine months ended September 30, 2014, total income secured of $432,232 was approximately 17% more than the same period in 2013. This increase was attributable to better financial results from Fundraising activities.

Expenses

Total operating expenses of $237,706 were 38% less than operating expenses for the same period during 2013. Research grant expenditures and costs associated with the 2013 CRN Family Conference were greater in the prior year as compared to the nine months ended September 30, 2014.

Net operating income of $192,526 for the nine months ending September 30, 2014 exceeded the net loss of $14,089 for the same period in 2013. Total increases in 2014 revenues and fewer year over year operating expenses generated these favorable financial results.

Net change in cash through September 30, 2014 and year end 2013 was an increase of $305,198. This increase was derived from increases in total income generated plus less operating expenses. In addition, the collection of donation receivable previously recorded at December 31, 2013 assisted in these results.

<table>
<thead>
<tr>
<th></th>
<th>July-Sept. 14</th>
<th>Jan.–Sept 14</th>
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<tbody>
<tr>
<td>Total income</td>
<td>$211,356.68</td>
<td>$522,232.38</td>
</tr>
<tr>
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<td>$57,804.21</td>
<td>$236,286.56</td>
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<tr>
<td>Net Ordinary Income</td>
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<td>$285,945.82</td>
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<tr>
<td>Total Other Expense</td>
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<td>$1,257.52</td>
</tr>
<tr>
<td>Total Other income</td>
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</tr>
<tr>
<td>Net Income</td>
<td>$152,394.95</td>
<td>$284,688.30</td>
</tr>
</tbody>
</table>
The next four days proved equally exciting in this beautiful, vibrant city on the ocean. I reconnected with two old friends, Pam Woodward and Frankie McGinnis and two new ones, Frankie’s niece, Jessica Slagle and her boyfriend Stefan Petrovic, a Biomolecular Physics PhD. student at Cal Tech. We were all treated to warmth, sunshine, and breathtaking views. Our hotel, located across from the Naval ship the Midway, and the Star of India was walking distance to restaurants and a short shuttle ride away from our destination, the San Diego Convention Center.

The exhibit hall at the convention center was huge and filled with hundreds of exhibitors, representing hospitals, pharmaceutical companies, medical supply companies and many other non-profits like us. We set up our both on Friday and enjoyed the sights around the city for the rest of the night. A highlight was Seaport Village, a beautiful shopping area filled with restaurants bordering the water.

On Saturday, Sunday, and Monday we arrived at booth 243 and greeted dozens of pediatricians who stopped by. We handed out brochures, journal articles, newsletters, pens, key rings, several pounds of chocolate and shared our stories. Some of the physicians had heard of Cystinosis, and some had not, but we made sure those “first responders” who stopped by our booth, knew about cystinosis when they left.

One young pediatrician expressed interest in becoming actively involved in CRN. We gathered her contact information. Another gave us a $15 donation, a first in all of our exhibiting experiences.

Too soon we were packing up our display materials, checking out of the hotel and hugging each other goodbye. We left feeling satisfied there were more pediatricians who now knew a little more about cystinosis because we were here.
By Victor Gomez

The 7th Cystinosis Symposium in Mexico City was a great success. One hundred fifty people enjoyed this year’s symposium. Nephrologists, nurses, students and practitioners were able to learn more about Cystinosis.

The speakers helped us to understand some of the highlights in cystinosis including: the importance of nutrition on a patient with cystinosis, and the kidney transplant. They described the difference between cystagon and the new 12 hour cysteamine treatment (Procysbi). They discussed the importance of cysteamine eye drops, and gave a complete report on what is going on with cystinosis patients in Mexico, Central and South America.

An important moment was when Jeff Larimore and his daughter, Sarah, sent a message on video to all participants. They encouraged all to collaborate and raise awareness on cystinosis. They stressed the importance of taking all needed meds and work hard for Mexican patients.

The Cystinosis Organization of Mexico would like to thank Orphan Europe and the Cystinosis Research Network for their valuable cooperation for making this event successful.

Dr. Leticia Belmont, Dr. Ewa Elenberg, and Dr. Craig Langman with two cystinosis patients in attendance.

Patients, families and physicians attending the 7th Mexican Cystinosis Symposium in August, 2014.
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- Insurance and benefits verification
- Financial assistance for eligible patients
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- Access to nurses and patient care coordinators Monday-Friday 8:00AM-8:00PM EST

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CRN Cystinosis Fellow Dr. Galina Nesterova Available to the Community

The CRN Cystinosis Fellow at the National Institutes of Health, Dr. Galina Nesterova has been working closely with Dr. William Gahl over the years, treating the cystinosis patients seen under the NIH protocol, participating in CRN Family Conferences, and speaking at professional meetings on cystinosis. Dr. Nesterova has become an expert in cystinosis and is available to consult with any family or health care provider who needs assistance in the diagnosis and treatment of cystinosis. She can be contacted at nesterovag@mail.nih.gov. Please feel free to contact her with any questions or concerns.

CRN Sponsors Gordon Research Conference: Lysosomal Diseases set for March 2015

The Cystinosis Research Network is proud to sponsor the 2015 Gordon Research Conference on Lysosomal Storage Disease in Galveston, Texas. It is a forum in which the latest findings on many different lysosomal disorders, including cystinosis, are explored in detail. The conference provides an international forum for the discussion of the latest scientific discoveries across a variety of fields, and for over 80 years, have been regarded as the world’s premier scientific meetings. The goal of the GRC is to bring together outstanding scientists from academia, industry, and government, ranging from senior principal investigators to Ph,D. students, in a collaborative setting that encourages the sharing of new ideas and unpublished research. CRN is proud to support the meeting by providing a grant of $3,000 which will be utilized to enable junior scientists to attend, which supports CRN’s mission of supporting new investigators in the field.
CRN to participate in KDIGO Controversies Conference on Nephropathic Cystinosis in December 2014 in Lisbon, Portugal

Kidney Disease: Improving Global Outcomes (KDIGO) is convening a Controversies Conference on Nephropathic Cystinosis from December 11-13 in Lisbon, Portugal. This conference will bring together approximately 50 experts to deliberate on the current state of evidence surrounding cystinosis treatment and diagnosis. The focus will be on both adult and pediatric cystinosis, and will also deal with the transition from pediatric care to adult care. Patient views and concerns will be a major part of the discussion – Christy Greeley has been invited to represent the community as a patient advocate. KDIGO Controversies Conferences are invitation-only events that typically involve topical plenary session presentations followed by focused discussions within pre-determined breakout groups. A final conference report summarizing the proceedings and deliberations will be published in a peer-reviewed journal. CRN is proud to participate and support this important conference.

Patients Needed for Growth Hormone Study at the National Institutes of Health

Cystinosis Research Network Cystinosis Fellow Dr. Galina Nesterova and coordinator Joy Bryant are still in need of more individuals to enroll in a new research study at the National Institutes of Health. The study will look at whether growth hormone (Humatrope, recombinant human Growth Hormone) may help prevent the loss of muscle that can sometimes occur in people with cystinosis. People with cystinosis are eligible to participate if they age 18 or over, are having muscle problems related to cystinosis, are compliant with their cysteamine therapy, and do not have cancer, high blood pressure, uncontrolled diabetes or significantly impaired kidney function.

The study would last for 2 years and involve 10-12 visits to the NIH. Participants would be assigned to a group that either receives daily growth hormone injections or no treatment for the first year, then would switch to the opposite treatment the second year, so that each participant would receive growth hormone for one year. Several tests will be included such as blood and urine, MRI and DEXA scans and other physician evaluations, all of which will be at no cost to the participant.

If you are interested in finding out more, please contact Joy Bryant at bryantjo@mail.nih.gov or (301) 443-8690 or Dr. Nesterova at nesterovag@mail.nih.gov.

Joy Bryant and Dr. Galina Nesterova work together on the NIH Growth Hormone Study for adults with cystinosis.
Education & Awareness Update

By Terri Schleuder– Vice President of Education & Awareness

As the leaves start to fall and 2014 nears and end, the CRN Education and Awareness Committee is hard at work raising awareness and planning for the future. CRN was represented at the 2014 Academy of Pediatrics (AAP) conference in San Diego, October 10th-13th. The event was attended by hundreds of pediatricians; the first responders in our community. Those who stopped by our booth left with brochures, stories, and medical articles about cystinosis. One young pediatrician who stopped by expressed a genuine interest in becoming involved in CRN. We gathered her contact information. (Read more about the AAP on pages 21 and 23.)

In 2015 CRN will attend the Pediatric Academic Society Conference (PAS) in April. It will provide another opportunity to educate and raise awareness among the pediatric specialists who attend to the needs of our children with cystinosis.

In this newsletter our featured family is the Long family, who share their journey of cystinosis with daughter, Lola. Two Adults with cystinosis, Tahnie Woodward and Jessica Jondle are also featured. I know you will enjoy their insightful words and amazing journeys. They are both inspiring, positive individuals with so much to offer this community about how to live each day to the fullest.

Planning for the 2015 CRN Family conference to be held in Chicago is well underway. It promises to be another exciting opportunity to bring together families, doctors, researchers and pharmaceutical companies, to provide support, and present the latest research, as we continue to battle cystinosis and support each other on this journey. If you have never attended a conference PLEASE come. I promise you it will be a life altering experience. If you have attended in the past come back; the opportunity to give and get support from families who know what this life is like is invaluable. The sharing of one gene connects us all as family.
As we begin 2015 the Education and Awareness committee is looking for more ways to meet the needs of the cystinosis community. Please see the questionnaire below and help us learn more about your needs and the ways we can help through offered activities and programs.

One recent suggestion has been to develop a mentoring program, matching young individuals with cystinosis with older ones, to offer support as life’s questions arise. Perhaps such a mentoring program could be expanded to include parents/caregivers, matching the newly or recently diagnosed families with “veterans” to offer direct support. It would have to be different then our wonderful social media opportunities that provide the chance to ask questions and get feedback.

Please help us help you by responding to the brief questionnaire below. Responses may be e-mailed to me at tschleuder@cystinosis.org or click on this link. https://cystinosis.org/news/announcements

Questions for the Cystinosis Community

Hello!

The Education and Awareness committee is seeking input from the Cystinosis community about our focus over the next few years to best meet the needs of our community. Your input to the following questions would be greatly valued as we plan for the future.

1. What needs do you have or see, that the Education and Awareness Committee could address over the next few years?

2. What ideas do you have about the direction the Education and Awareness committee should take over the next few years?

3. Would you be interested in participating in a mentoring program if CRN developed one, matching adults with cystinosis with adolescents, or parents of older patients with parents of those newly diagnosed.

4. Any other ideas or thoughts to share?

Please direct responses to: Terri Schleuder, VP Education & Awareness tschleuder@cystinosis.org
CRN Development Update

By José T. Morales, Vice President of Development

So, the summer has come and gone and the cold temperatures of Fall are upon us. I am sitting by the fireplace, with a nice fire blazing away, the air is filled with the roar and popping sounds of the wood being consumed by the fire. Could there be a better time to sit down and write my Development article? I didn't think so. I have to tell you, we have had a very successful year of fundraising events. Whereas the events and amounts raised are impressive; what is truly remarkable is the number of people involved. Sponsoring a fundraiser and raising money is not the easiest of things to do. In fact, for most of us, it is an uncomfortable thing to do. That said, there are a few families that have consistently answered the call and new families engaging in raising funds for CRN to enable the organization to execute its stated vision and mission:

**Vision** - The Cystinosis Research Network's vision is the acceleration of the discovery of a cure, development of improved treatments and enhancement of quality of life for those with 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.

So, why did I decide to include our Vision and Mission statements? It is because I believe this is one of the major differentiators for CRN. We cover everything from research, education and awareness and family support. For the record, this is a very broad scope but necessary none-the-less. In addition to the breadth, we also are becoming more active and recognized on an international basis. In order for CRN to achieve its objectives, we need to raise funds. It is really fairly simple. In order for us to accomplish our stated vision and mission, we need to be able to fund and execute our programs.

Your Development Committee continues to make progress in its efforts to increase the number of fundraising events and the amount of funds raised.

**Development Committee**

**Corporate Sponsorship**

Jeff Larimore - JLarimore@arnoldfamilycorp.com
John Maccarone - johnm2maccaroneplumbing.com
Deb Reed - dk_reed@hotmail.com
Fund Raising

Shannon Keizer - Slkeizer@hotmail.com
Katie Larimore - klarimore112@sc.rr.com
Tim Miller - Tim.Miller@chrobinson.com
Briana Smythe - bri_ana15@hotmail.com
Jen Wyman - jwyman@comcst.net

Administration

Christy Greeley - Greeleycd@aol.com
Jen Wyman - jwyman@comcst.net

It is hard to believe we have started the last quarter of the year and have raised approximately $750,000 year-to-date; recently completing three major events during the month of October.

2014 Event Calendar (September - December, 2014)

September

- Detroit Free Press International Half Marathon - Jenni Sexstone
- Chandler's Three Fundraisers (Eggs Galore, Veggie Garden Feast & Caring School Friends) - Clint & Annie Moore
- Hike for a Cure - Jessica Jondle

October

- An Evening of Laughter - John & Arlene Maccarone, Marybeth Krummenacker, Christy Greeley, José & Velyna Morales
- The Village Club of Lincolnshire Kick'n Cystinosis - Dave & Christy Greeley
- Masquerade Ball For A Cure Charity - Ina & Victor Gardner

Event calendar (cont. on page 32)
Development Update (cont. from page 31)

November

- Anjie and Nelly Polanco Birthday Letter – Rachel DeLomba
- Running For Mason & Livia Stilke – Joy Parker and April Corrigan
- A Celebration of Life Letter – Shannon Keizer
- Tee (shirt) Fundraiser – Tahnie Woodward, at:
  http://todayisamiracle.bigcartel.com

December

- Chandler’s Chance…A Christmas Palooza For Cystinosis - Clint & Annie Moore

A number of the events are highlighted in this edition of the newsletter so be sure and read all about the fun, excitement and satisfaction one experiences when sponsoring a fundraising event!

We continue to make progress in growing the number of events and people involved with fundraising. I cannot tell you how important it is for us to be able to raise funds for the CRN to fulfill its stated vision and mission. Please give serious consideration to becoming involved in some capacity with our fundraising efforts. The Development Committee is available to assist you in thinking through whatever fundraising activity you are most comfortable with in sponsoring. How can we expect others to advocate for us if we do not take a proactive stance for ourselves? Please reach out to one of the committee members or myself, jtm01@optonline.net / 203-722-9292, to become involved.

Join us as we continue our efforts to positively impact the future of our children.
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%202019%20202012.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
https://cystinosis.org/how-to-help/donate

Checks payable to CRN—Keith and Billy Croce Memorial Scholarship
C. H. Robinson Golf Event another Great Success for CRN

By Tim Miller

This year the 8th annual Cystinosis Charity Golf event had a personal connection to C.H. Robinson. On June 7th 2014, Lola Long, daughter of Information Technology Manager Jim Long, was our honored guest. This little heart breaker greeted each foursome with a shy smile and a thank you as she made the rounds with her grandparents who also joined us.

Lola was diagnosed in 2013 with cystinosis. I am privileged, as a member of the CRN board, to have assisted Jim and his wife Melissa to connect with CRN. Since our first conversation the Long family has been involved raising awareness for CRN, as well as supporting the golf outing.

The event was another great success. We gathered over $77,000 on a perfect day in June. The light winds of the day refreshed everyone. It was without a doubt the best weather we have had for the event.

As always, Tahnie and Pam Woodward attended the event with their families. Their support with the day’s events was priceless. CRN sent José Morales to join us as well, as the voice of the network. I want to thank everyone who attended the event, sent me money or helped. I take great pride in those who...
surround this event each year because they know how impactful the financial contributions are for the Cystinosis Research Network.

The 2015 event is set for June 6th at 9 am. I am currently working with Jeanne Oki, who is a longtime sponsor of the CRN golf event hosted by C.H. Robinson. She is exploring what it might take to get permits to expand the C.H. Robinson event into a fun walk or run. Look for updates later. This could really take the event participation to new levels.

“Dream, Achieve, Inspire” CRN Art Exhibit

To the Worldwide Cystinosis Community,

The Cystinosis Research Network is hard at work on a brand new project for our worldwide community! “Dream, Achieve, Inspire” is an art exhibit that will debut at the 2015 CRN Family Conference in July in Chicago. All patients with Cystinosis are invited to contribute their art including paint, drawing, photography, sculpture, poetry, jewelry, music or fabric art of any kind. Our goal is to have every country affected by Cystinosis represented. All works of art will be used in the exhibit.

We are looking for art from all ability levels from professional artists to children’s art. We want as many artists with Cystinosis as possible. Only artists WITH Cystinosis will be included. Our goal is to showcase the amazing talent in our community as well as raise awareness about Cystinosis through art from around the world.

This will be a TRAVELING exhibit. After its debut in Chicago, “Dream, Achieve, Inspire” will be able to travel to any Cystinosis gathering in the world. This collection will belong to the entire community. All efforts will be made to get the exhibit to any Cystinosis organization requesting a visit.

All art must reach me February 1, 2015. Each contribution will be catalogued and added to the Exhibit. I will need the name of the artist as well as contact information and a short biography to go on display. Please include a picture of the artist as well. This promises to be a breathtaking and emotional tribute to our very unique community. Please consider being a part of our artistic love letter to Cystinosis patients around the world!

Most Sincerely,
Katie Larimore

Contact information
Klarimore112@sc.rr.com
Cell: (803) 873-2128
232 Fair Ridge Lane
Blythewood, South Carolina
29016
USA
No Fundraiser is too Small!

By Clinton Moore

Over the summer Chandler Moore decided he wanted to do "The Worlds Smallest Fundraiser". He wanted to try and sell some of our eggs that we pick up every day from our backyard chickens. He set the price at 2 dollars per dozen and the sales began. After just a few days we were overwhelmed with so many orders that we had to create a waiting list. The five chickens we had was proving to not be enough. Twelve more were added to the flock to help keep up with demand. All the orders were eventually filled and this fundraiser is still on-going with a list of steady purchasers that stop by every week or biweekly.

As the summer continued and we were overrun by the amount of vegetables we were getting from our garden, yet again Chandler stepped up and got to work. He set up a table next to the road, made a sign, and sat there for hours. Since we live on a back road out in the country, sales were extremely slow, so he decided to place a jar on the table and hope that people would leave their payment in it. Every day when he returned from school he would run straight to it and would usually find a few dollars in his jar. The smile on his face when he came inside was always priceless.

He donated 100% from both fundraisers to the Cystinosis Research Network and will continue so as the egg sales still continue. Chandler says that every dollar counts so there is no such thing as a fundraiser that is too small!!!
I recently had the opportunity to represent CRN at a meeting in Alexandria, Virginia. For more than 30 years, NORD has served as the voice of the rare disease patient community, uniting individuals and disease-specific organizations to drive progress for all. As NORD’s slogan says, “Alone we are Rare. Together we are strong”.

The meeting was attended by over 500 people from Advocacy, Government and the Pharmaceutical industry as well. A broad array of speakers opened the meeting beginning with the topic of exploring the FDA’s flexibility in approving novel orphan therapies. Frank Sasinowski, is a member of the NORD Board of Directors and the author of *Quantum of Effectiveness in FDA’s Approval of Orphan Drugs*, a paper published a few years ago. In his article, Frank demonstrated that the FDA has had a history of flexibility in the approval of orphan therapies since the enactment of the Orphan Drug Act of 1983. In fact, in this published paper cystagon is #41 on the list of first 100 drugs approved by the FDA as a direct result of that legislation. The Cystinosis community would probably not have any medication without that piece of legislation.

We then heard from other speakers, Dr. Janet Woodcock is the director for the Center for Drug Evaluation and Research at the FDA, who illustrated once again the significance of this ground breaking law. As the day continued there were breakout sessions with speakers, including our own Dr. Jess Thoene, who moderated a panel on Transforming Diagnosis – Promoting Diagnosis and Targeting Treatments. There were lively discussions and questions and answers in every session about topics such as Advancing Therapies for Pediatric Rare Diseases, Harnessing the Opportunities and Power of Social Media to name a few. I believe my favorite was titled, *The New Role of Patient Organizations in Accelerating Research and Promoting Diagnosis*. One of the panelists was my friend Donna Appell, Founder and President of the Hermansky-Pudlak Syndrome Network. Donna gave us all a lot of laughs as she said that leaders in the patient advocacy community have to wear many hats. She demonstrated this to us by wearing a variety of hats; a captain’s hat because we are all captains of our ship; a reporter’s hat because we have to have the ability to tell our stories when asked; a hat that was a light bulb because we have to be the innovators and come up with ideas for future research and finally a hat with a rainbow because we all need to look for that pot of gold to pay for everything!!!

It was another great opportunity to network with key leaders in advocacy as well as industry and government. These meetings are always extraordinary to me as I look at them as the opportunity to keep Cystinosis at the forefront and I ALWAYS say I represent the community as a whole and I am honored to do just that. “Alone we are rare. Together are strong”.
Pediatric to Adult Transition Patient Forum
Hosted in Music City USA

By Katie Morrison & Jeff Larimore

Adults managing with Cystinosis and their families joined together in Nashville, Tennes-see, on August 16th to share experiences and insights on transitioning from medical care and guidance provided by their teams of pediatric physicians to adult physicians. The night’s conversation was hosted by Dr. Bettina Ault, Pediatric Nephrologist with Le Bonheur Children’s Medical Center and the University of Tennessee Medical Center. Dr. Ault, also was able to provide comments from Dr. Colleen Hastings, Adult Nephrologist from UT Medical Center, in the area of adult medical care management and transition.

Families throughout the Mid-South region were in attendance. The attendees included the Langley family from Georgia (Eddie), the Joynt family from Alabama (Mitch, recently married and on his honeymoon at the time – Congrats to the Newlyweds!), the Kloete family (Katie Roy), and Katie Morrison, CRN Board Member, from Tennessee. Representatives for Sigma Tau and Raptor Pharmaceuticals along with Jeff Larimore were also in attendance.

The evening’s conversation was dynamic and diverse. The topics within Transition included medical care and treatments, employment opportunities, health insurance and future health issues and opportunities.

Consensus was consistent that transition to adult medical care is challenging throughout the community. Many of the adults expressed frustration with how often they needed to provide an initial education to the adult physicians of the magnitude of daily management requirements of Cystinosis. This concern alone has been a major barrier to transition. Plus, years of guidance from a pediatric team that has provided stability raises the question of the urgency to transition to adult care. Dr. Ault’s suggestions to the cystinotic adults were to be straightforward and open about their medical history and inform the physicians that medical resources regarding Cystinosis are available from advocacy organizations such as CRN to assist in their education of the condition.

Families expressed the challenges of health care insurance coverage for siblings with Cystinosis that are, or about to be, 26 years old. The benefits of the Affordable Care Act have been helpful the last few years to the families. However, intertwined with the demands of maintaining consistent employment and insurance eligibility, consistent health care coverage is always at risk. If families or adults reaching 26 years of age are in need of assistance with health care coverage, Raptor Pharmaceuticals may be able to provide some assistance and options through the RaptorCares program.
In regards to current medical treatments available, the adults remarked to follow the recommendation of their medical teams and expressed the importance of medication compliance and an overall wellness program.

Looking to the future, the attendees expressed a sense of optimism but also wanted to see if research in progress can benefit the community’s overall well-being. There was some discontent expressed that the social media circles too often express excessive negativity and accomplishments are hardly recognized or praised. Dialogue among the group targeted the challenges of marriage and raising children and inquired about the possibility of physical disabilities caused by cystinosis. Having an open forum where all the topics were on the table for discussion provided a great experience for all.

There will be announcement of more patient forums being sponsored by the Cystinosis Research Network. Those in attendance in Nashville highly recommend attending because questions can be addressed with experienced medical professionals and service providers plus the network of Cystinosis family can be broadened.

2015 Family Conference (cont. from page 1)

around the world, meet and renew friendships with other families, have the chance to participate in research studies, and interact one on one with many of the world expert clinicians treating and researching cystinosis today.

Located only steps away from the Magnificent Mile and Navy Pier, the DoubleTree by Hilton Chicago Magnificent Mile puts you within reach of the windy city’s best dining, shopping and entertainment. Our fabulous location, in the heart of Streeterville, is within minutes of Navy Pier, Chicago Water Tower, John Hancock Building, CTA Red Line, Tribune Tower, Millennium Park and the Lake Michigan. Getting to our location is easy if you are coming from the airport, since we are less than 45 minutes from O’Hare and Midway. For more information on the hotel please visit their website at www.doubletreemagmile.com.

Registration materials will be available in early 2015 on the CRN website and will also be mailed to families. Special room rates have been negotiated with the hotel and will be made available to conference attendees.

We look forward to seeing you in in Chicago in July 2015!
Village Club of Lincolnshire 2nd Annual Kick’n Cystinosis Event Raises over $7,000

By Robin Babbo, Village Club President

On Sunday, Oct. 5, over 220 players came out and kicked Cystinosis at The Village Club’s 2nd Annual Kick’n Cystinosis charity kickball tournament benefiting Cystinosis Research Network.

It was cold and windy and everyone knows North Park is always 20 degrees colder than the rest of town. But players played and stayed – buying raffle tickets, dancing to the DJ and eating and drinking too.

We raised $7,000 in Three Hours!

Thank you to our Kickn’ Committee of volunteers – Philanthropy Chairs Susie Durlacher and Laura Gens; Jennifer Qualley, Roberta Hancock, Christy Greeley, Laura Russo, Sue Wynne, Diane Gillis, Jenn Booker, Lisa Dean, Jodie Halazonitis, Michelle Moody, Mindy Abern, Abbe Kalina, Ginger Engel, Lauren Dardick, Melinda Simonson, Caralee Levinson, Karen Friesen, Angie Depew, Kim Kutnick, Molly Shapiro, Michelle Weinstein, Julie Schectman, Millie Caner, Dave Greeley, Maria Arne, Kristin Keevins, Connor Horton, Mike Muth, Hannah Charak, Mark Hancock, Greg Immell, Jeff King, Michael Durlacher, and Robin Babbo.

Attendees enjoy the day at the 2nd Annual Village Club of Lincolnshire Kick’n Cystinosis event.

And there’s more...Thank you to our generous sponsors La Rosa, Prairie House, The Fresh Market, Einstein’s, Creative Edge Chicago, Tamarak, Lincolnshire Sports Association, and DJ BenJammin. Special thanks to the Village of Lincolnshire for their support with North Park.

It TRULY takes a Village!
Dave, Jack, Alex, and Christy Greeley.

The LeBeau, Julian, Greeley, and Ellerbrock Families Kick’n Cystinosis

Alexis LeBeau, Kennede Julian, and Evan LeBeau

Jakob Ellerbrock, Evan and Alexis LeBeau, Kennede Julian, and Jack Greeley
Degree of Pocahontas Women’s Group Selects CRN as their Charitable Organization

By Beverly Ames

(Editors Note: CRN is honored to receive a donation from the 'Degree of Pocahontas’, a women’s auxiliary of The Improved Order of Red Men, (IORM). Among the goals of this organization, first established in 1885, is to help those in need with organized charitable programs. Beverly Ames, who recently served as Great Pocahontas of Massachusetts, selected CRN as her charity organization to support. Please read about her personal connection to Cystinosis below.)

My name is Beverly Ames. I have a great niece that has suffered from cystinosis. At the age of two she was diagnosed. At the age of fifteen she had a kidney transplant. I just finished my term as Great Pocahontas of Massachusetts. As I served, I had to raise money for a charitable organization, and I chose CRN. I spoke to other councils around Massachusetts about cystinosis. Each council donated money to my project. We also raised money by selling chances on an American Girl Doll (Indian Doll), mystery bag and other raffles. Money was also donated by some of the Red Men. I am very pleased to have raised $2,316.50 for the Cystinosis Research Network. I hope this will help future children in need of help.

Sincerely,

Beverly Ames, Past Great Pocahontas, in Freedom, Friendship and Charity
Lola’s Story

By Jim Long

My wife Melissa and I have four children of which, Lola, age two, is our youngest. Lola has two older sisters, Ella, age eleven, Ava age ten and one older brother Jake, age six. Lola’s story started in much the same way as most other children with Cystinosis. She was our largest child (in a group of “runts” 😊) by quite a bit. Lola was registering 60% and 80% in height and weight respectively until approximately 6 months when she began to lose weight.

From 9-12 months, Lola continued to lose weight. At approximately 9 months the vomiting and the unquenchable thirst started. She had days where we were convinced there was more coming out of her stomach then was actually going in. On the day of her first birthday Lola went into Minneapolis Children’s hospital with dehydration and failure to thrive. She would end up spending nearly the next month there.

The time Lola spent in the hospital was difficult -- in particular for her. Between the no food and no liquid orders, the blood draws and fitful nights, we were watching her waste away before our eyes. After about two weeks spent in the med surg. rooms, they moved Lola to the ICU. We were new too, and struggling with all of the procedures she was being put through. Many of which, might now seem almost commonplace. Lola was continuing to go downhill. It really hit us when the hospitalist told us we might want to begin preparing for a scenario where Lola may not go home.

During Lola’s third week in the hospital, and second week in the ICU, they diagnosed her with Fanconi’s Syndrome. This ended up being the breakthrough that we needed and her diagnosis moved fairly quickly from there. Within a few days, Lola had been diagnosed with Nephropathic Cystinosis. We began reading anything we could get our hands on regarding the disease. It was an emotionally polarizing experience I am sure many parents of Cystinotic kids have had -- to feel relief actually having a diagnosis but, have that relief overshadowed by the uncertainty of the diagnosis.

We were set to begin our first dose of Cystagon when we received a call from Lola’s nephrologist. There was a Procsybi study beginning at Lurie’s Children’s hospital in Chicago and they would like Lola to participate. Remarkably, we received the call on the same day that Lola’s first course of Cystagon arrived at our house;
the course that had been delayed by two weeks, due to mix-ups with the pharmacy and insurance company denials. Had she received the Cystagon on time, she wouldn’t have been eligible for the study as they were looking for Children with no history of Cystagon use.

In July 2013 we made our first study trip to Chicago. Lola was going to receive her first Procysbi and we were anxious to start taking any steps to slow the cysteine damage. She had a GJ feeding tube at this point and the Procysbi wouldn’t push through. Back to Minneapolis.

In August we returned to Lurie’s. Lola’s tube had been switched out for a larger G tube and the Procysbi passed through just fine. We were excited that she was in the program and having access to doctors and researchers familiar with Cystinosis was fantastic. All the medication dosages still needed quite a bit of fine-tuning and Lola’s weight was still very much down. But, we were excited to have what felt like a real starting point for progress. She couldn’t communicate what she was feeling but, you could tell when her levels were off, as she’d become very lethargic and not at all herself. The vomiting was continuing at a fairly heavy pace and we ended up having a couple transfusions when her hemoglobin levels dropped very low.

For most of the fall of 2013 we would make bi-weekly trips to Lurie’s. Although we thought we were seeing improvements, Lola’s progress was slow. Raptor encouraged family members to be part of the process, so we would often take one or more siblings along. Allowing the other kids to see the process, and that she was in good hands, went a long way to ease their concerns (we have some worriers).

Around Christmas time we started to see a marked improvement. The vomiting frequency dropped considerably and her labs seemed to have stabilized, most of the time at least. We also noticed that she generally seemed to feel better. Her energy level was up and she almost always wanted to “play with the big kids”.

The Long family, Jim and Melissa, with their children, Ella, Ava, Jake and Lola (with the pink hat.)
Other than the frequent Dr. appointments and scheduling around meds, we really don’t treat Lola any differently from our other three kids. She continues to hit her developmental milestones for walking and talking and this fall started gymnastics (“nastics”). Being included in things that she sees her siblings be a part of is important to Lola and us. This summer the family took a two week road trip through the Midwest, stopping in Nebraska, Colorado and South Dakota to visit family before returning to Minneapolis. Plenty of water jugs and car seat liners went along with us. It was the highlight of Lola’s summer! She got to swim in the hotel pools, ride horses at her uncle’s ranch, and spend time with cousins.

After Lola’s diagnosis, we were looking at fundraising events on the CRN website and came across a golf tournament in Utah sponsored by the CH Robinson Salt Lake City office. Coincidently, I’ve worked for CH Robinson for 10 years in Corporate Information Technology. My wife and I made the trip with her parents and Lola. We were thrilled to be part of the event for 2014 and are looking forward to 2015. What a fantastic tournament and what a great group of volunteers and sponsors raising nearly $80,000!

Birthday Letter Campaign for Anjie and Nelly Polanco Held in November

By Rachel Dalomba

Another year has gone by and as the end of 2014 swiftly draws near, we find ourselves being catapulted into the holidays. Just as you open that little fun-sized Kit Kat bar you stole from your child’s Halloween bucket, store shelves are being stocked with everything you need – and can completely do without – to prepare a Game of Thrones inspired feast for your loved ones and adorn your lawn with the most elaborate decorations. The holiday season is a time for reflection, hope, gratitude, joy, and giving as we celebrate with family and friends to welcome what we hope will be a prosperous and healthy new year.

In our house, there are two very important dates that make the holidays that much more meaningful. Anjie and Nelly were born 17 years ago on November 10th and December 5th marks the 7 year anniversary of their life-saving kidney transplant. I still can’t believe that my girls are turning 17. They are juniors in high school, learning to drive, and planning for college. Where did the time go? I ask myself this question every year as I remember the night they were born. I was a young mom - alone, scared, and in premature labor. At 10:02 PM, Anjie was born at 4.06 lbs. and Nelly at 5.03 lbs. an hour and thirteen minutes later at 11:15 PM. Yes, the twins were born an hour and
thirteen minutes apart! They spent some time in the NICU, as preemies normally do, but they were ready to go home in no time. I brought home two very healthy, happy, and thriving little girls. However, as the twins approached the 7 month mark, their health took a turn for the worst.

After countless visits to the pediatrician and the ER, the girls were diagnosed with cystinosis just before their 1st birthday. Cystinosis is a rare 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 and/or the possibility of death at approximately age nine. Cystinosis also causes complications in other parts of the body; including muscle wasting, difficulty swallowing, diabetes, and hypothyroidism. It is estimated that at least 2,000 individuals worldwide have cystinosis.

The girls were immediately treated with the cystine depleting drug, cystagon, upon diagnosis along with a cocktail of other medications they would need around the clock to stay alive and preserve the health of their kidneys. They both had to be fed via G-Tube in order to receive the nutrition they were missing from the loss of appetite, dehydration, excessive vomiting, and diarrhea, which were both symptoms of cystinosis and side effects of their medications. Due to the around the clock medicine schedule and feeding pumps alarming at all hours of the night, not one of us will ever experience a full night of uninterrupted sleep. By the age of 9, Anjie and Nelly’s kidneys were failing and they started dialysis treatments.

On December 5, 2007, Anjie and Nelly received the gift of a kidney transplant which made national news as they were the first siblings to receive a simultaneous renal transplant and to each receive a kidney from the same cadaver donor. This precious gift gave them a second chance and improved their quality of life; although, a transplant does not cure cystinosis. They will continue to fight this disease and overcome many obstacles for the rest of their lives. Since having the transplant, Anjie was diagnosed with Post Transplant Lymphoproliferative Disease, or PTLD, a type of lymphoma that is caused by immunosuppressant therapy after an organ transplant, along with other transplant and cystinosis related complications.

It has been quite a journey. Fast forward to today, the girls’ health is stable thanks to newly FDA approved treatments and for the first time in 17 years; we are all able to enjoy full nights of uninterrupted sleep. The girls are able to focus on normal, age-appropriate things, like passing the ACT, Drivers Ed, their love of the visual arts and special effects makeup, and taking their kid sister for long fall walks through the forest. We are all grateful to be exactly where we are on this journey and are eager to celebrate another birthday and holiday season.
Normally, teens are planning their birthday parties and writing birthday wish lists but not Anjie and Nelly. Instead, every year, the twins request that I write a birthday letter soliciting support and donations from our family and friends to the Cystinosis Research Network in lieu of a party and gifts.

The money that is raised for the Cystinosis Research Network, a volunteer, non-profit organization, is used for supporting and advocating research, providing family assistance, and educating the public and medical communities about cystinosis. CRN’s vision is the acceleration of the discovery of a cure, development of improved treatments, and the enhancement of quality of life for those, like Anjie and Nelly, having to endure Cystinosis.

So I ask that as you begin to prepare for the holiday season, you make a little room in your heart to honor this special birthday wish and consider making a tax deductible donation to the Cystinosis Research Network. Your support means so much to Anjie and Nelly and continues to makes a difference.

Sincerely,

Rachel DaLomba (mom to Anjie and Nelly)
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!

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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________________

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 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 CRN’s Mission with Your Donation

☐ 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:_____________________________________________________

Please check all that apply:

_____Friend
_____Individual with Cystinosis
_____Parent of Child with Cystinosis
_____Professional
_____Family
_____I am interested in volunteering for CRN. Please contact me.

Search the Web with GoodSearch & Raise Money for CRN

Every time you use GoodSearch.com to search the Web, a donation is made to the Cystinosis Research Network! GoodSearch.com is powered by Yahoo!, so you get the same 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 goodsearch.com and select Cystinosis Research Network where it says "Choose your cause." Then search like you normally would!

The more people who use this site for CRN, the more money is earned. So please tell your friends and family!

Make Purchases at GoodShop & Raise Money for CRN

GoodShop.com allows you to purchase through most online retailers, and a percentage of your purchase goes to the Cystinosis Research Network! There is no additional cost to you!

To get started, go to goodshop.com, choose CRN as your charity, and click through the link on the GoodShop page to get to your favorite retailer. It’s that easy!

GoodShop will donate up to 30% of your purchase to CRN. Some of the hundreds of retailers include: Best Buy, iTunes, Home Depot, Amazon, Barnes & Noble, Dell, Banana Republic, Macy’s, Target, Wal-Mart, Ann Taylor Loft, Chicos, Coldwater Creek, American Eagle Outfitters, and many more!
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.

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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 individuals.

**Donate to CRN by Selling on eBay**

CRN is registered 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!

Learn more about the CRN Amazon Smile Program by clicking on the link below:

https://org.amazon.com/npo/portal/marketing-tools/ref=org_prt_qwh_mt
Cystinosis is a rare, genetic, metabolic disease that causes an amino acid, cysteine, to accumulate in various organs of the body, including the kidneys, eyes, liver, pancreas, brain and white blood cells. Without specific treatment, children with cystinosis develop end stage kidney failure at approximately age nine. The availability of cysteamine medical therapy has dramatically improved the natural history of cystinosis so that well treated cystinosis patients can live into adulthood.

CRN Vision and Mission

Vision. The Cystinosis Research Network’s vision is the acceleration of the discovery of a cure, development of improved treatments, and enhancement of quality of life for those with 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.