Cystinosis Research Network Builds Relationships in the Medical Community

The Cystinosis Research Network continues to be dedicated to networking within the medical community. Several CRN board members have attended nephrology conferences and symposiums within the last few months. CRN representation is vital at these events in order to continue to convey our mission and vision to medical professionals, pharmaceutical companies, and others who support our cause.

In November, 2005, Mary Beth Krummenacker and Frankie McGinnis attended the American Society of Nephrology conference in Philadelphia, PA. The goal of the CRN attending was to educate adult nephrologists about the CRN so that they can share information with their patients, and let them know we are here for them. As more children with cystinosis transition to adulthood, it is essential that adult nephrologists are equipped with the information and resources to treat them. Dr. Bill Gahl spoke to over 200 nephrologists at the conference about this transition.

L to R ---- Lesli King, Carol Hughes, Gregg LaPointe, Marybeth Krummenacker and Wendy Perrow attended the University of Miami Pediatric Nephrology Seminar in Miami Beach in March. Sigma Tau was recognized by Dr. Jose Strauss, the organizer of the meeting, as a long time supporter of this very important gathering of doctors and medical students from around the world. Carol and Marybeth represented the Cystinosis Research Network and were honored to be asked to be guests at a dinner hosted by Sigma Tau. Sigma Tau recently committed to a $15,000 grant to CRN for their educational programs for 2006. A big thank you to Sigma Tau for their continued and ongoing support of CRN and the cystinosis community.
Message from the President

José T. Morales

2006 is well underway, and there is a lot of activity within the CRN. As we shared with you in our Fall newsletter, this year we are focusing our efforts on a multitude of fronts...exploring ways to broaden our communications and increasing our reach within our community, reviewing our organization protocols to heighten our efficacy in representing our interests to our service providers, proactively reaching out to our ever growing membership, etc. So, without further adieu lets jump right into it...the following is a listing of major events/highlights:

Governance
The Nominating Committee pulled together an impressive slate of candidates for our Board. It is with great pleasure we announce the new Board membership:

| Karen Gledhill | Education Committee |
| Kathleen Harrison | Membership Committee |
| Dan Julian | Education Committee |
| Mack Maxwell | Education Committee |
| John Shepperd | Vice President-Development |

Additionally, we have committed to a more proactive outreach program to our international cystinosis community via greater communications and collaboration. The intent is to better leverage and share the medical research information being sponsored and, wherever possible, leverage our joint scale to advance the community’s interest.

Research
We are considering how best to broaden and accelerate the identification and sponsorship of research projects focused on improving quality of life. Also, we are in the midst of determining how best to create and fund a Cystinosis fellowship program in collaboration with the National Institute of Health and the Cystinosis Research Foundation. To that end, the 2006 Call for Research Proposals has been issued and is included in this newsletter.

Another important achievement to report is that the Scientific Review Board’s membership has recently confirmed their continuing commitment by renewing their three year terms of service on the Board. Christy has also initiated efforts to increase the number of the SRB’s membership to provide greater flexibility in the review of growing research applications. CRN and CRF have utilized the SRB jointly over the past year – currently, CRF is in the process of establishing their own SRB in order to keep up with their increased number of review meetings resulting from their phenomenal fundraising efforts. CRN is happy to have worked with CRF in this way over the past year and we look forward to other collaborations in the future.
Development

John Shepperd is our new Vice President for Development and Committee Head. John has had an immediate impact as he has brought new perspectives on how improve our fund raising effort….he has established a target of $250,000 and a stretch target $300,000. We currently have $200,000 already targeted through scheduled events/activities. This leaves a short fall of $100,000 and $200,000 respectively. Please reach out to John and sign up to sponsor a fund raising event.

Education and Awareness

We continue to commit resources and energy in order to represent the cystinosis community at important medical conferences and meetings throughout the world. CRN has gained the respect of the medical community by being a visible presence at these meetings in the past. We have attended or plan to attend the following conferences for the first half of 2006:

- March 9-14 - 33rd Annual University of Miami Pediatric Nephrology Seminar - Miami Beach, Florida
- April 30 – May 2 – American Society of Pediatric Nephrology/Pediatric Academic Societies Annual Meeting – San Francisco, California
- June 30 – July 2 – International Cystinosis Meeting - Netherlands

Family Support – We have streamlined the hosting and domain of our website, and it is being maintained by board members. Look for future improvements in navigating, access to material and update/maintenance of information.

The 2007 Family and Medical Conference will be held in San Antonio Texas is July, 2007. Check the Cystinosis website at www.cystinosis.org for more details as they become available.

Folks, we have come a long way in a relatively short period of time. We have achieved a lot of things for the betterment of our children and adults….for the betterment of our immediate family….and of our extended family as well. In spite of all of our many accomplishments, much remains to be done. With everyone’s help, we will continue on our course. Please consider joining us in whatever capacity you can.

José Morales
President,
Cystinosis Research Network

In the giving spirit: Carly Cuffle and Morgan Heckman went around the neighborhood collecting money for cystinosis during the Julian’s Texas Hold Em’ night. See page 22 for complete story.
CRN Attends Medical Events

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Mary Beth and Frankie connected and reconnected with representatives from Sigma Tau, the pharmaceutical company that is committed to bringing the eye drops to market. Sigma Tau stated that they are “committed to seeing the eye drops brought to market and they are working very hard to accomplish this goal.”

In March, 2006, Carol Hughes and Mary Beth Krummenacker attended the 33rd annual Pediatric Nephrology Symposium at the University of Miami. Dr. Jose’ Strauss organizes the symposium. The setting is more intimate than most and included 140 Pediatric nephrologists/fellows and medical students.

The CRN’s attendance fee was used to scholarship two medical students to attend the symposium. Mary Beth and Carol were again invited to a dinner with Sigma Tau, Dr. Strauss presented Sigma Tau with an award at the dinner, and Sigma Tau agreed to give the CRN an educational grant for the 2006 calendar year. Mary Beth and Carol also established a relationship with Dr. Leticia Belmont and Victor Gomez from the Cystinosis Foundation-Mexico and made a commitment to work together to support those living with cystinosis in South America.

Finally, in May, 2006, Garry and Carol Carol Hughes and Pam Woodward attended the American Society of Pediatric Nephrology/Pediatric Academic Societies in San Francisco. Dr. Kaskel, Dr. Inglefinger, and Dr. Langman are all past presidents of this organization and sit on the CRN Scientific Review Board. Thousands of Pediatric Nephrologists, Fellows, and Medical Students from around the world attend this conference to learn the latest developments in nephrology and to network with one another. Carol and Pam made critical connections to key people with Orphan Europe, the distributor of Cystagon in Europe and South America.

Carol Hughes, Dr. Frederick Kaskel, Marybeth Krummenacker - Dr. Kaskel stopped to talk to Carol & Marybeth at the recent Miami meeting. Dr. Kaskel has been the driving force behind CRN attending these professional conferences and educating the medical community about cystinosis. He also plays an active role on our Scientific Review Board and has become a strong advocate for CRN throughout the world of pediatric nephrology. Dr. Kaskel is the Chairman of the upcoming International Pediatric Nephrology Meeting that will be held in NYC in 2010. CRN will play an active role in the planning stages this spring.
Victor Gomez, Marybeth Krummenacker, Carol Hughes, Dr. Leticia Belmont - CRN hosted a dinner for Victor and Dr. Belmont in Miami and renewed our commitment to work closely for the betterment of the South American cystinosis community. Victor and Dr. Belmont have committed to being the cystinosis connection to the South American community for CRN.

The CRN proudly displays information at events in the nephrology community.

Dr. Jose’ Strauss is congratulated by his daughter, Bernarda Strauss, M.D. and Garry Hughes after receiving the ASPN’s most coveted honor, The Henry L. Barnett Award, at their Awards Luncheon, May 1st in San Francisco during the Pediatric Academic Societies’ 2006 Annual Meeting.
Cystinosis Research Update
By Christy Greeley, Vice President, Research

Call for Research Proposals
The Cystinosis Research Network is pleased to announce its 2006 call for research proposals. Proposals may be submitted to CRN for review and consideration. CRN utilizes a Scientific Review Board comprised of leading experts on the disease of cystinosis which reviews grant proposals and submits funding recommendations to the CRN Executive Committee. More specifically, the SRB provides independent, objective review and recommendations regarding each research proposal utilizing grant review guidelines established by the CRN Executive Committee and in accordance with the mission of the organization.

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

Proposals must be submitted by June 15, 2006. Qualified proposals will be reviewed during the annual Scientific Review Board meeting in July. The Cystinosis Research Network Grant Proposal Guidelines may be accessed on the CRN website at www.cystinosis.org.

Research Committee
In addition to the latest call for research proposals, the CRN Research Committee has been involved in a variety of activities since last summer’s conference and Scientific Review Board meeting. Elva Smith has joined the Research Committee, adding her wealth of medical and research experience to our group. Elva recently represented CRN at a roundtable in Washington, D.C. sponsored by the Genetics & Public Policy Center and the Genetic Alliance which focused on the lack of regulation and standardization for genetic testing. CRN looks forward to representing the cystinosis community with regards to this and a variety of other research issues through Genetic Alliance and other advocacy and policy groups in the future.

In addition, the Research Committee has begun work on the reorganization and expansion of the research publications and other medical information contained on the CRN website. In the coming months be prepared to find an easier to use and more comprehensive body of medical information on cystinosis available online for your reference.

Scientific Review Board
We are proud to announce that all seven members of our SRB, including chairman Dr. Bill Gahl, have renewed their terms of service for another three years. In addition, four new members have been invited to join in order to better address the issues involved in the yearly research funding review. Information about these new board members will be available on the CRN website as soon as they are confirmed.

The Cystinosis Research Foundation has recently established their own separate SRB due to the overwhelming success of their fundraising efforts and the resulting sharp increase in research funding activity. CRN is pleased to have been able to collaborate with CRF during the past year via use of a joint SRB. We look forward to further collaboration to ensure that the research needs of the community continue to be met. To this end, CRN is working to establish a research fellowship to attract new researchers to this field – CRF has also been working towards establishment of such a program.

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Cystinosis Research Update

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Research Updates

CRN is currently involved in funding five research projects which represent a commitment of nearly $120,000 this year, with further expenditures resulting from this year’s call for proposals projected to bring this total to over $200,000. Following are updates from these five studies:

The following yearly update was provided by Dr. Trauner for her study which was originally funded by CRN in 2003:

Title of Project: Early Intervention Trial For Visual Processing Deficit In Cystinosis
Doris A. Trauner M.D. Principal Investigator
2/27/06 Progress Report

Hypothesis: Children with cystinosis will improve their visual processing skills by repeated, graded presentations of visual stimuli

Specific Aims: To determine whether a unique program of computerized visual stimuli, presented in slowly increasing speed of presentation and complexity, will improve visual processing in children with cystinosis.

Progress Report: Currently, we have 7 children enrolled in the study. Five children have received their baseline cognitive testing, and two more are scheduled for baseline testing in March. Four children have completed the 3-month follow-up testing, and 2 children are scheduled for 6-month follow-up testing. Of these children, 2 have completed the computerized intervention program, and 3 more are currently participating in the computerized intervention program. We are actively recruiting more participants for this project.

We have experienced some unexpected difficulty in finding families who are willing to participate in the study. Although many parents express concern about their child’s school performance, they are reluctant to commit to the 12-week time requirement of this study. Thus, we are somewhat behind our expected goals in recruitment. We are, however, actively looking for more families to participate in the study.

When we initially began the study almost 2 years ago, we screened a number of children as potential participants in the study. These children received screening and baseline testing because they were also participating in another study that is ongoing in our laboratory. Since there was a delay in beginning the actual intervention portion of this study, it was necessary to administer new baseline cognitive testing in order to have an accurate idea of current neuropsychological and academic functioning.

Future Plans: We will continue to enroll subjects into the study when possible. We hope to have most of the study completed by the end of August of this year, but this will depend on our success in recruiting families into the study and on subject compliance in terms of consistency in performing the intervention.

Dr. Jess Thoene’s study entitled “Increased Apoptosis Produces the Phenotype in Nephropathic Cystinosis”, originally funded in 2004, received final payment this spring. His final report was published in the Fall 2005 edition of the CRN newsletter and can also be found on the CRN website.

Three studies were funded as a result of the 2005 Scientific Review Board meeting. The first, “Tissue Repository for Cystinosis” by Dr. Jess Thoene, has been put on hold temporarily as a result of Hurricane Katrina and the resulting displacement of Dr. Thoene’s facilities at Tulane University in New Orleans.
The second, Dr. Corinne Antignac's project, "Development and in vivo testing of novel therapies for cystinosis" is well underway, with a 12 month progress report due this fall.

The third project, "Design and Synthesis of Novel Prodrugs for the Treatment of Cystinosis" by Dr. Donald Cairns, is also underway and he has the following preliminary information to report:

“The prodrug work is going very well and a number of compounds have now been synthesised and fully characterised. So far, all the compounds have been odourless (or at least, without an unpleasant smell) and the ones which have been tested have proved tasteless. We now need to ensure that removing the taste and smell doesn't also remove the activity, so in the next few months we plan to shift the emphasis from discovery chemistry to biological evaluation of the compounds to see how well they lower cystine levels in cells. The aim of the work remains the production of an oral form of cysteamine that doesn't taste bad and doesn't smell bad and we're very grateful for the support furnished by CRN."

Look for further progress reports and information regarding the next Scientific Review Board meeting and new projects funded as a result in the Fall/Winter edition of the CRN newsletter and on the CRN website.

Participants Needed for Dr. Dohil’s New Study

Dr. Dohil and Dr. Schneider at the University of California, San Diego, are proud to announce that they will soon be starting their next clinical study. The aim of this research study is to find out if by making changes to the Cystagon tablet it will be possible to take Cystagon every 12 hours instead of every 6 hours. The changes made will stop the tablet dissolving in the stomach. It will instead dissolve in the small intestine. These changes are called enteric coating. The doctors believe that this way more Cystagon will get into the body and its positive effect will last longer. The substance being used for the coating is Eudragit and is produced by Röhm America in New Jersey.

The study will start in late spring 2006 and has 3 parts. During the first part the patient will continue their regular Cystagon therapy. The therapy will be monitored closely for 4 weeks by testing white blood cell cystine levels every 2 weeks. These tests will be done at the patient’s regular physicians office.

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

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

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

Travel expenses for the volunteer and one parent to San Diego will be covered and the volunteers will be compensated for participating in this study. If you are interested in participating and would like more information, please contact Meredith Fidler, PhD, at (619) 543 2049 or _mfidler@ucsd.edu_ (mailto:mfidler@ucsd.edu).
By Karen Gledhill
As part of their “Mystery Diagnosis” series, the Discovery Channel was looking for individuals with rare diseases who had a hard time getting a diagnosis. Joey Jordan’s journey to diagnosis was familiar to many, so members of the cystinosis community recommended that the Jordan’s appear on the show. Richard Jordan expressed that his family is always willing to do whatever they can to get the word out on cystinosis and help other families. The show’s producer contacted the Jordan family and asked them some questions to see if they fit the needs of the show. Once they passed the screening, they were on their way!

Mary and Richard Jordan have four children. Caitlin is 13. Joey and Patrick are twins that were adopted at birth, and Connor is 5. Joey is quite a bit smaller than Pat. They are both part hispanic although Joe is a tan redhead and Pat is a fair-skinned blonde with blue eyes.

The entire Jordan family as well as Mary’s mother and sister and Joey’s main doctors, Dr. Ernst and Dr. Orloff, were involved in the shoot. They spent 12 hours taping at the studio one day. On the following day, a video crew followed them around at home. The process brought back feelings the Jordan’s had when they did not know what was wrong with Joey, and they were at their wits ends dealing with the situation.

The Jordan’s were very happy with how the show turned out. They did feel that the show gave the impression that the diagnosis went quickly once they started narrowing down the possibilities. The real time frame was much longer and there were periods of time between the initial diagnosis of Diabetes Insipidus and the Cystinosis diagnosis that were difficult and filled with uncertainty.

While talking to one of the producers, the Jordan's discovered that the producer had grown up in Bethesda and was good friends with the Gahl's! In addition, Joey’s doctor, Dr. Orloff, was one of the original Cystinosis researchers at the NIH and he passed on his efforts to Dr. Gahl when he left. They discovered what a small world it really is.
Meet the New CRN Board Members

John Shepperd—Vice President Development
Kim and John Shepperd live in San Antonio, Texas. They grew up there and went to high school together but didn't start dating until many years later. John is a partner in a medical equipment sales company where his job description includes VP of Marketing and Chief Financial Officer.

The Shepperds have two children; John Ben is 5, and Ava is almost 1 yr old. John Ben was diagnosed with cystinosis at the age of 18 months at the Texas Children's Hospital in Houston after a long, drawn-out ordeal. Ava was diagnosed in utero and started cystagon at about 8 weeks old. At this time, she has not developed Fanconi's Syndrome.

Both John Ben and Ava are doing well with relatively few complications.

Karen Gledhill—Director Education Committee
Karen Gledhill is an adult with cystinosis from New York State. She is one of the oldest with late-onset cystinosis. Karen learned her kidneys were failing at age 20. At that time, her sister, Deb, was also checked out and diagnosed with kidney problems. Her sister's clinic was familiar with Dr. Schneider at UCSD, and that is how Karen and Deb were diagnosed with cystinosis. Both had also been told most of their lives that they had strange crystals in their eyes!

Karen received a kidney transplant at age 32 from a cadaver and is now 24 years post transplant!

Karen works in the advertising field and has unselfishly volunteered her time in leadership positions for her local Kidney Foundation and TAO (Transplant Awareness Organization). She has also been involved with the Transplant Olympics since 1992 and the Rochester Eye and Tissue Bank.

Kathleen Harrison—Director Membership Committee
Kathleen Harrison lives in Marana, AZ. She became a foster parent after working as head supervisor for a group home that served dependent children aged 0-18 years. She found it frustrating that she could not form a lasting bond with these children and wanted to do more. Kathleen adopted three of her foster children: Ramon suffers from mild retardation and fetal alcohol effect; Logan suffers from post-traumatic stress disorder, and Danielle suffers from cystinosis. She was diagnosed at 13 months.

Kathleen has an extensive history of working with children with special needs. She was the youngest director of mental health programs for young adults at the YMCA. She has been a Sunday School teacher, director, and nursery coordinator, and she worked for an organization called VisionQuest, a mobile that provides an alternative to youth incarceration. Kathleen is currently the President of the Pima County Foster Care Association.

Dan Julian—Director Education Committee
Jan and Dan Julian live in Central Illinois. They both grew up in Riverton, Illinois, and met in grade school. They started dating their senior year of high school and both graduated from Purdue University. Jan has a degree in Pharmacy, and Dan has a degree in Industrial Design. Jan currently works for Walgreen's, and Dan works at Peak Product Design, a company he started six years ago.

The Julians have two children. Taylee is five years old, and Kenadee (with cystinosis) is three years old. Both Taylee and Kenadee share a birthday, exactly two years apart. Kenadee was diagnosed at 11 months by her pediatrician and her team in Springfield, IL. Upon diagnosis, Kenadee spent 6-7 weeks in the hospital in Springfield and in St.Louis Children's. The first 6-9 months after diagnosis were very rough, but Kenadee has been doing very well lately. She will start PreSchool in the fall of this year. The Julians are nervously trying to prepare themselves for this new and exciting chapter in their lives!

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Meet the New CRN Board Members

Mack Maxwell-Director Education Committee
Mack Maxwell graduated from the University of Texas at Arlington with a Bachelors of Science in Information Systems. He is currently a lead programmer analyst for Tarrant County College. He has been in the Information Systems industry for 20 years.

Mack was born on 4/9/64 and diagnosed with nephropathic cystinosis around the age of 7. He had his kidney transplant at age 11 in 1975. In 1999, Mack began going to the NIH to receive treatment for cystinosis. One of his objectives as a CRN board member is to emphasize the importance of physical fitness. Mack’s hobbies are working out, sports, and traveling.

Mack Maxwell Visits Mexico

In February, Mack Maxwell had the opportunity to visit Victor Gomez and have some fun in Mexico City. Victor is a 23 year old adult with cystinosis and founder of Cystinosis Mexico AC. Mack visited Victor before and has had the pleasure of meeting cystinosis patients in Mexico. Mack and Victor arranged Mack’s first trip to Mexico after the Las Vegas conference in 2001. This time Victor arranged some fun with Dr. Leticia Belmont and two of her friends from Costa Rica. They all went to the southern part of Mexico City and took a river boat cruise. This exciting cruise included food, drinks, and the famous mariachi bands.

Victor and Mack also did sight-seeing on an open air bus tour that went through historic Mexico City. This was an excellent way to see many sights in a short period of time. Mack expressed that it was really nice spending time with Victor’s family and friends, and sampling lots of tasty Mexican food.

Alejandra, Isabel Ibarra, Dr. Leticia Belmont, Victor Gomez, and Mack Maxwell in Mexico City
The Cystinosis Research Network (CRN) and the Cystinosis Research Foundation (CRF) continue to partner in the fight against cystinosis. The following announcement is an excerpt from the CRF newsletter:

The CRF is excited to announce that Kevin Sharp will be the guest speaker at our Fifth Annual Natalie’s Wish Fundraiser on Thursday, June 1, 2006 at the Balboa Bay Club in Newport Beach, California.

Kevin Sharp, award-winning vocalist, entertainer and cancer survivor, will inspire us all as he shares his experiences and the lessons he learned while battling cancer. The foundations of his strong beliefs are never giving in and never giving up. Kevin knows the most powerful gift we have in this life is – HOPE.

As a teenager, Kevin was a gifted athlete who excelled in several sports. He began experiencing fatigue and unexplained pain in his leg, which was later diagnosed as a rare form of bone cancer (Ewings Sarcoma) that had spread to his lungs.

As a senior in high school, Kevin was told that his chance of survival was slim. Uncertain if he would live six months, Kevin was introduced to the Make A Wish Foundation, which grants wishes to children with life-threatening illnesses. They honored his wish of meeting producer/performer David Foster, whose friendship sustained Kevin through two grueling years of chemotherapy, experimental drugs, and radiation treatments. It also opened a door for Kevin to pursue his goal to become a successful country artist.

To everyone’s surprise, Kevin went into remission in 1991. He has never forgotten the generosity of the Make A Wish Foundation, and currently acts as a national spokesperson for the group. He was also honored with the prestigious Wishgranter of the Year Award, which singled him out for the devotion, dedication and inspiration he provides the children. To date, Kevin is the only “wish child” to become the wish request of other wish kids, making his wish experience come full circle.

A platinum debut album, Measure Of A Man; scores of award nominations; and a string of chart-topping hits including She’s Sure Taking It Well, If You Love Somebody, and the highly acclaimed Nobody Knows – which held the top spot on Billboard’s Country Singles Chart for an astonishing four weeks– mark his debut as the best by a new male country singer in five years.

Kevin is a living example of the power of a wish and we are blessed to have him share his music and his story with us at Natalie’s Wish on June 1, 2006.
Hello to everyone in the Cystinosis community. I would like to share how things are going in Mexico related to cystinosis. It has been four years since Cystinosis Mexico started, and we have had many obstacles along the way. Support to rare diseases is not always available. We now have 12 patients with cystinosis in Mexico. Only two do not receive cystagon because they are on dialysis.

We formed a medical advisory group, and three of Mexico's largest Pediatric hospitals know about cystinosis. We had our 3rd medical symposium last January, and it was a success. Thank you to Dr. Craig Langman and Dr. Ewa Elenberg from the USA for being our special guests. We had planned a dinner benefit event, but unfortunately, it was cancelled. We are now preparing for our first fundraising event and will have more information soon.

In July, 2005, we attended the CRN’s conference in Utah and met many new people. We learned a lot about research and talked to members of the CRN Board. We enjoyed being there!

Finally, last March, we had the chance to go to the Pediatric Nephrology Symposium in Miami for the first time. We ran into Mary Beth and Carol in the gorgeous lobby there! We talked to many doctors from South America. They were asking for support from us. We were told their cystagon delivery is not complete. The supplier sends smaller doses than the patients need. We have been in touch with Pharmcare, which is the cystagon supplier to Mexico, and it seems we will start to help South America. Stay tuned for more information!

Thank you to the CRN for letting me share a little of our work here in Mexico City.

Best Wishes—Victor Gomez

www.cystinosismexico.org
Sierra was born May 28, 1990 to Rock Ace and Pamela Kay Kofford Woodward. She was the long-awaited and only little sister of Utahna (Tahnie) Woodward.

Si-Si chose to leave this life and return to what she believed would be a better place, on March 28, 2006.

At the time of her death she was a sophomore at American Fork High School. Sierra loved her animals and had a passion for writing poetry and for sewing. She had her dream of one day having a book of poems published and of owning her own designing and clothing firm. She looked forward to the hunting and fishing trips with her Dad and traveling, ballgames and shopping with her Mom and sister, Tahnie.

A “Tribute To Her Life” was held April 3, 2006 and burial was in the American Fork City Cemetery.

The “Sierra Woodward Sibling Scholarship Fund” has been established and donations can be made in her memory C/O:

Cystinosis Research Network
10 Pine Ave
Burlington MA 01803
Sierra

She was a ray of light, on a cloudy day,
A creative whirl wind, doing things her way.

Her zest for life, could make you smile
And she could push you to the limits, to the extra mile

Her eyes would twinkle as she joked and teased
Her laughter would make you feel so at ease.

She was thunder and sunshine all wrapped into one
But mostly she was just plain fun!

We will never be able to fill the place in our hearts
That will cause us to mourn and tear us apart

But we have wonderful memories that will carry us through
She was loved by those around her, More than she ever knew.

—EJ Thornton
Kidney Care Quality Improvement Act  
(S.635, H.R.1298 )Needs Our Help

By Karen Gledhill

Rep. Dave Camp (R-MI) has introduced H.R. 1298, the Kidney Care Quality and Improvement Act. This legislation seeks to address long standing goals of the National Kidney Foundation that include improving how the Medicare program provides services to Americans with kidney failure, also known as End Stage Renal Disease (ESRD). While there have been many medical advances since the inception of the ESRD program in 1972, Medicare has failed to keep pace with some of these changes. H.R. 1298 provides a way to ensure that patients with kidney failure receive high quality care.

H.R. 1298 seeks to improve the ESRD Program by:
• Creating public and patient education initiatives to increase awareness about chronic kidney disease (CKD) and to help patients learn self-management skills
• Providing Medicare coverage for CKD education services for Medicare eligible patients
• Establishing an outcomes-based quality demonstration project to study how best to structure incentives for providers
• Ensuring quality through improvements in the ESRD payment system, including phasing in an annual update mechanism for dialysis providers that, unlike all other Medicare providers, do not have an update mechanism for payment to account for real changes in prices and inflation.
• Aligning incentive for physician surgical reimbursement for dialysis access to promote quality and lower costs
• Establish a uniform training for patient care dialysis technicians
• Improve ESRD coverage by removing barriers to home dialysis and creating an ESRD Advisory Committee.

This bill has the strong support of the patient advocacy community and providers, including Kidney Care Partners, the Renal Leadership Council, the National Kidney Foundation, the American Kidney Foundation, the American Nephrology Nurses and the Renal Physicians Association.

The National Kidney Foundation is urging everyone to write your member of Congress in support of this legislation.

To find your member of Congress:

1. Go to the following website:  
   http://www.capwiz.com/c-span/dbq/officials

2. Enter your 9 digit zip code and find your Representative. If you only know your first five digits, check your mail to see if it includes the last four digits. If not, you can find out the last 4 digits from your local post office. Many 5 digit zip codes are split by 2 or more congressional districts.
Joanie Devine Receives Kidney Transplant

Joanie Devine received a kidney transplant on January 18, 2006 at Brenner’s Children’s Hospital in Winston-Salem, North Carolina. Joanie was diagnosed with cystinosis when she was 13 months old. She is now a junior in high school and will be 17 on June 13. Joanie LOVES animals and has a horse, three inside cats, an inside German Shepherd, and a pot belly pig that just showed up on the front porch recently!

Joanie received a cadaver kidney. She had an uncle who was two tests away from donating his kidney to her, but when a cadaver came in, the Devines did not want to pass up the opportunity. Joanie was on a waiting list for six months, but she did not have to endure dialysis. Joanie did not have any complications during the surgery, but three days later, her blood pressure dropped low, and her heart rate sped up. A fever accompanied these symptoms. The symptoms only lasted a day, and doctors still do not know what caused them.

Joanie’s mom, Portia, cannot say enough good things about the care Joanie received at Brenner’s Children’s hospital. Her advice to others waiting for a transplant is to have your bags packed at all times! They got the phone call at 7:30pm on a Tuesday night. They didn’t expect it and didn’t have bags packed. Portia did have a “last minute checklist” on the refrigerator door. The list included who to call, medicine to remember, etc. Portia also recommends to have plans made for pets ahead of time. Give whoever is taking care of them a key to the house in advance, and keep any and all phone numbers you may need with you at the hospital.

Joanie had both of her native kidneys removed because they were spilling so much sodium and potassium. Doctors said if they left her kidneys in, they would only end up causing more damage, and she would have to take three additional medications. It really took about a month and a half for her to notice that she felt better than before the transplant. The medicine she takes and her medication schedule completely changed. She is only taking two medications, cystagon and potassium, that she was on prior to transplant.

Her eating and drinking habits changed drastically. Prior to surgery, Joanie craved spicy and salty foods, ate condiments in bulk, and had to have Mexican food one day a week, and the Olive Garden one day a week. She would eat banana peppers, olives, and mushrooms by the jar and would drink a lot of water, milk, and coffee.

Since the surgery, Joanie eats sweet foods instead of salty. She doesn’t need so many condiments. She hasn’t wanted Mexican food or the Olive Garden, and she hasn’t touched jars of banana peppers, olives, and mushrooms!

Prior to transplant, Joanie was getting up to go to the bathroom and drink water 5-8 times per night. Now she is able to sleep ALL night. Joanie is currently applying for her first summer job and will be attending college in Fall, 2007 to be a Registered Nurse.
On March 11, 2006, Ashley Kazian competed in the Miss Greater Greer USA pageant and won! Ashley is a close friend of the McGinnis family and competed with cystinosis as her platform. Ten-year-old Laura McGinnis has cystinosis. Ashley made a special brochure with her and Laura’s picture on it to distribute at public appearances. She also has the CRN’s website address on her comp cards (below). The program for the pageant included a piece about the Cystinosis Research Network and what it is. Ashley says she is inspired by Laura and all individuals with cystinosis.

Ashley is a former Eastside High School student—the school in South Carolina whose student body has raised a tremendous amount of money for the CRN.

Ashley also won the swimsuit competition at the Miss Greater Greer pageant. She will participate in Miss South Carolina USA the weekend before Thanksgiving. This has been a lifelong dream of hers, so she is going to give it her all. THANK YOU, Ashley! You are a remarkable young woman, and everyone impacted by cystinosis appreciates your commitment to raising cystinosis awareness. Good luck in November!
CRN Sponsors Super Pro Truck Racing

Dave Xavier will be competing in the Super Pro Truck division in the Nascar Weekly Racing Series at the Riverhead Raceway, located on Long Island in Riverhead, New York. Xavier will have a host of sponsors for the 2006 Super Pro Truck season, but has decided to make the Cystinosis Research Network his primary hood sponsor.

"My crew and I decided that it would be hard to find a more deserving and worthwhile cause than to highlight the efforts of the Cystinosis Research Network," Xavier said. "It is an organization that has close ties with my crew and we wanted to do take whatever steps possible to help them. We are proud to have their logo on our hood. We also put www.cystinosis.org on our rear spoiler. Perhaps, with any luck, we can say we played a small role in finding a cure for this rare illness."

Xavier, a Skip Barber Racing School graduate, and long-time driver of the Coram Fire Department Racing Team, is looking forward to getting back into the action at Riverhead Raceway. Xavier earned some experience in the Riverhead Charger ranks and this year will run in the prestigious and highly competitive Super Pro Truck ranks.

In addition to the Cystinosis Research Network, Dave Xavier and the DFX Motorsports team will be sponsored by the following: Empire State Regional Council of Carpenters Local 7, Dr. Michael Sherman Family and Cosmetic Dentistry, Archer Insurance, CSF Surety Consultants, USA Truck Works, White Post Wholesale Growers, The Vinyl Answer, and J&J Auto Body.

Dave Xavier made the Cystinosis Research Network his primary hood sponsor of his Super Pro Truck for the 2006 season.
Fundraising Brings us Closer to a Cure

Please consider hosting a fundraiser to help the CRN accomplish its ultimate mission of finding a cure for cystinosis. If you need more information, please contact the CRN at: CRN@cystinosis.org or 1 (866)-276-3669

Note Card Fundraiser

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

Design options are floral, poinsettia, snowflake or a script initial. The inside is blank. The CRN logo and website address is on the back. A set of 8 cards and envelopes is $10.00 (US) which includes shipping and handling.

Go to http://www.cystinosis.org/news090804.html to download an order form.

Announcing the 3rd Annual Family Fun Day in Honor of Jack Greeley

The third Annual Family Fun Day in honor of six-year-old Jack Greeley will be held on August 26, 2006 at the Tamarak Country School, 23970 North Elm Road, Lincolnshire, IL. All proceeds will go to the Cystinosis Research Network.

The afternoon activities will include swimming, horse rides, a moonwalk, music, dancing, games, prizes, face painting, basketball, food, dance troupe performance, and crafts. Silent auction and raffle items will include birthday party packages, travel opportunities, spa gift certificates, restaurant gift certificates, tickets to Chicago Bears, Cubs, and White Sox games, signed sports items, American Girl items, golf packages, Odyssey dinner cruises, and much more!

The family fun day started three years ago when a group of the Greeley’s friends decided they wanted to do something to make a difference in Jack’s life and others who suffer from cystinosis. The first two Family Fun Day events raised a combined total of $22,000. Visit jacksfamilyfunday.org for updated information about the event.

Get Ready to Make Some Magic!

Magic at Milleridge, a dinner dance that benefits the CRN, will be held February 24, 2007 at Milleridge Cottage in Jericho, NY. For more information, contact Mary Beth Krummenacker at 516.931.6785 or mkrumm@aol.com
The 2nd Annual Lowdown at the Hoedown was held in February this year at the historic Anhalt dance-hall about 25 miles North of San Antonio. The weather was beautiful. We had a good turnout and raised over $18,600 for cystinosis research!

This year, we added more activities for the kids, such as a moon bounce, washer toss, and the Wiggle-Waggle train in addition to the holdovers from last year: face painting, temporary tattoos, and the petting zoo. The “train” is actually a large riding lawn mower towing several brightly colored, cut-out 55 gallon barrels. The kids loved it! We had live music, barbeque, Mexican food, beer, and soft drinks. We were happy to see some of our cystinosis family make the trip to San Antonio, including the McCallas (without Kevin…apparently a 12 noon start time is too early for University of Texas art majors!) the Ricos, Frankie McGinnis, and Pam Woodward.

We included the silent auction of (mostly) children’s artwork, which again was a big part of our success. Although we didn’t raise quite as much money this year as we did last year, we were able to fine tune the process, and it was much easier from the planning standpoint. Next year will be even better.

As I posted in a recent email, most of the CRN fundraising is done by the same families year after year. We really need to broaden the scope of this effort, and I encourage ALL of you to hold a fundraiser of some type. Believe me, it may be a lot of work, but it is a lot of fun, too. You can start by asking your friends and family to help you sponsor a cookout in your backyard, and sell dinner plates for $6. Go to a printing shop, and make a poster for a few bucks to tell everyone about cystinosis. Churches, Rotary Clubs, and other social organizations are also excellent resources. Don’t be afraid to ask for help….you’ll be surprised at the support you receive. We had a fantastic team of volunteers at the Hoedown this year, some of whom I’d never even met before. People want to get involved, but sometimes they just don’t know how to start.

Best of luck!

John Shepperd
The Julians Host Texas Hold Em’ Night

Our First Annual Texas Hold’em Fundraiser for The Cystinosis Research Network was a huge success! I had several people tell me how smooth and well run it was. A HUGE THANK YOU goes out to Brian Cuffle for managing and hosting the tournament. I think everyone agreed it was a great time, except maybe for Big Red. Big Red was the first to be eliminated, (sorry Big Red) followed quickly by several others, including myself. The ailing, Dr. Chad Burmeister, took out the first 5 or 6 people very early on and had a commanding chip lead! Somehow, Dr. Burmeister managed to lose it all just as quickly as he amassed his fortune. Side note: Dr. Burn was eliminated before his wife Cheryl!! From there on out, the chip lead was pretty much held by my neighbor, Jack Brackney. Congratulations to the Top 9: Tom Combs, Bill Seagle, JP Young, Ryan Miller, Jack Brackney, Tim Stoecker, Bill Lamkey, (I can’t believe I’m typing these two names) Jay “9-3 off-suit” McCullough and Jeff Koger, yes Jeff, not Matt. Most of us have not competed in a tournament this size so, you should all be proud of yourselves!! It all came down to Bill Seagle and Jack Brackney with Jack having the chip advantage. The night was ended when Bill checked a ‘straight’ on the flop. Jack went all-in and Bill called for the win… The real winner of the night though went to the Cystinosis Research Network!!!

We were able to raise $2,020.00 for CRN in Kenadee’s name. We had several winners that donated all or a portion of their winnings back to CRN. Thanks guys!! A special thanks goes out to Jodi and Garred “Big Red” McHatton, Bill Lamkey, Andy Martin, Christy and Kenny Morrison, Doranne “Mom” Julian, Pam “Mom-in-law” Roesler and my beautiful wife, Jan, for the awesome spread of food that was provided. Heck, that was worth the price of admission by itself. We even got a surprise donation from two beautiful, little girls, Carly Cuffle and Morgan Heckman. Unbeknownst to anyone, these two went around the neighborhood asking for donations and in total raised $39 for CRN. Talk about two giving little angels! Thanks girls!!

I also want to extend my sincerest appreciation to the entire Cuffle Family for hosting and managing this unbelievable night. We raised a lot more than I had anticipated and can hardly wait for The Second Annual Texas Hold’em Fundraiser for The Cystinosis Research Network in honor of Kenadee Reese Julian.

Again, thanks and hopefully we’ll see you at the next one, where you know I’ll be “all-in”.

Sincerely,

Dan, Jan, Taylee, and Kenadee Julian

Earl Julian —Bluffing as usual!
Doranne Julian Hosts “That’s My Pan!” Fundraiser

While walking through the Exposition Building at the Illinois State Fair last August, I spotted a product that I thought would be a great Christmas gift for my daughters-in-law. It was a personalized 9X13 baking pan and lid. I was in a hurry (I had to get a corn dog and elephant ear before returning to my work site in the Senior Center) so I just took a brochure and left. A couple of days later, as I was going through all the literature I had accumulated at the Fair, I ran across the "That's My Pan" brochure. As I reviewed the brochure again I saw that the "That's My Pan" aluminum lids were texturized with your choice of four colors and 100 pictures. A cute saying like "From the kitchen of." or "Made with love by." followed by a name was also engraved on the lid. The high quality aluminum pan was engraved with the name as well.

I began to see this pan as the answer to my dreams!!! I could get one for each of my daughters-in law, one for my mother, one for my best friend, one for my boss. Hey, wait a minute. what is this about a fundraiser? I checked the website and discovered that there was a fundraising option. Long story short - I showed the brochure to several co-workers and friends and the pans practically sold themselves. We sent two orders, one for 68 pans and the other for 84 pans and made $1,000 for CRN. We were proud to send a check for $1,000 to CRN in honor of our granddaughter Kenedee Reese Julian, on her third birthday, February 24, 2006.

For anyone else who would like information about "That's My Pan" visit www.thatsmypan.com or call 1-800-332-2707. They were a great company to work with, very friendly, easy to contact, and responsive to all inquiries. By the way, my co-workers are asking if we will be doing it again with some of the other products offered.

Sincerely,
Doranne Julian

---

Kenadee Julian

Taylee and Kenadee Julian

That’s My Pan! Merchandise
Road Race Participants Run for Alex Weaver

By Karen Gledhill

This past April, for the third consecutive year, members of the Commonwealth's Attorney Office ran in the Ukrop's Monument 10K and dedicated their efforts to help fund research for the Cystinosis Research Network. This year they raised over $4600 for the CRN! The Ukrop's Monument Ave 10K is a road race filled with rockin bands, high energy cheering groups, and an awesome post race festival that combine to turn one of America's most beautiful residential streets into the country's best 10K course.

This sanctioned race, which takes place every year in Richmond, Virginia attracts racers from around the country. Also included as part of the days activities is a children's one mile run. The First Market Mile Run provides a first class running experience for youngsters, ages 6-12, of all abilities.

Alex Weaver's mom, Angie, works at The Commonwealth's Attorney's Office. The fundraiser was the idea of a co-worker in the prosecutor's office, Duncan Reid. Duncan took an interest in Alex and came up with the idea of using the race as a fundraiser for cystinosis research. Angie's office has been very supportive of her and everything that the family has been through. They were quick to react and received approximately 100 donations from people for the upcoming race.

Alex was diagnosed at 11 months. He had been throwing up over a weekend and his mother, Angie took him the doctor. The nurse practitioner did blood work and determined their were problems. She sent Alex and Angie to the hospital. A new pediatric nephrologist had recently started and tested Alex for Cystinosis. The diagnosis was confirmed.

Alex is doing great. He is in the 75th percentile for weight and 50th for height. He does not have a g-tube. He goes to pre-school five hours a day and looks and acts like a typical three year old. He has 2 other siblings, Ashley and Austin, who do not have cystinosis.

Friends Rally Around the Bingers

Kellen Binger received a kidney transplant on April 26 at University Hospital in Madison, Wisconsin. Kellen is 8 years old, and his kidney came from his dad, Tim. Kellen loves swimming, hockey, and the Wisconsin Badgers. Several fundraising efforts have taken place or will be taking place in honor of Kellen.

- The Madison Feis (Irish Dance Competition) will be donating the proceeds from their June 3 raffle to the Cystinosis Research Network. Various items will be raffled, including American Girl dolls. Kellen’s sister will be participating in the competition.

- One of Kellen’s classmates, Melissa Heilman, and her family collected $75.00 and wanted to give it to the Bingers. The Bingers forwarded it to the CRN.

- Nicole (12), Molly (11), and Luke (9) Kollman each received $20 for Christmas and donated it to the CRN. The Kollmans are good friends of the Binger family.
Jack Greeley’s 6th Birthday Fundraiser

The Greeley Family of Illinois has once again reached out to friends, family, and colleagues and asked that donations be made to CRN in honor of their son Jack’s sixth birthday. This is the fourth year the birthday letter fundraiser has taken place -- to date for this year’s fundraiser, they have raised over $26,000! In addition, through the years several members of their community have been inspired to organize their own fundraisers for CRN, including golf outings and the annual Tamarak Family Fun Day held each year in August. You can read this year's letter, as well as past years, on the CRN website at www.cystinosis.org.

Fundraising Ideas

Some wonderful and creative fundraisers are featured in this issue of the newsletter. Here are some more fundraising ideas that are easy to execute.

- Have a “spa day”—Charge a fee for attending and sell tickets in advance. If someone cannot attend the “spa day,” see if they will make a donation. Have someone who sells cosmetics and/or body care products come do facials on your guests. See if they will donate a percentage of their sales to cystinosis. Have a massage therapist volunteer their time to do shoulder and foot massages. Have volunteers deliver appetizers and ice water with lemon to guests while they get pampered! Invite a candle salesperson, and see if they will also donate a percentage of their proceeds. Raffle off a “spa gift basket.”

- Donate in lieu of gifts. How many times have you received an invitation to a “monumental” birthday party requesting that you don’t bring gifts? If you know someone celebrating a monumental birthday, see if they will request that guests donate to the CRN in lieu of gifts.

- Involve a direct sales consultant. Tupperware, Home Interiors, Pampered Chef, and Tastefully Simple all have fundraiser programs. You would be surprised at how much more people will buy if they know it is for charity.

- Bartend for charity! If you or someone you know can mix a drink, ask a local drinking establishment if they will let you bartend for charity. Advertise the night of the event in advance. All bartending tips go to cystinosis. Combine with a silent auction. Bar owners love it because it brings in patrons!
My husband and I had always hoped for more children. We had the perfect family, two girls, seven and eight-years-old, and another on the way. I’ll never forget the excitement of having another baby in the house. It was exactly one year since we’d lost a child from a miscarriage. This new baby was our long-awaited miracle. We all agree that the day she was born was one of the happiest days of our lives. She was so beautiful, such a blessing! She was the type of baby that caught everybody’s eye. She turned heads. She still does. She was such a happy infant and seemed like the “typical toddler.” This changed all too soon!

It was June, 2004. Tina was ten months old. Our happy little girl became fussy, refused to eat, and vomited profusely. We presented in the ER multiple times over the next many months, spending a week each time, not knowing if our little girl would make it through another night. The physicians were puzzled as to what was going on with Tina’s little body. They would place her on a heart monitor. Her potassium was dangerously low. They would rehydrate her, and send us home. It was both tiring and frustrating! No one knew why our little angel was close to death.

Finally, in March, 2005, after finally being diagnosed with Renal Tubular Acidosis, then Fanconi Syndrome, our pediatrician referred us to two specialists—a Nephrologist and a Metabolic/Genetic physician—at Doernbecher’s Children’s Hospital in Portland, Oregon. After one month in the hospital, with so many tests and procedures—IV’s, heart monitors, PICC line, nasal tubes, x-rays, ultrasounds, barium enema, upper GI, and the constant blood tests, we finally received a long-awaited prognosis. Tina, now 17 months, was diagnosed with cystinosis. She had surgery for a gastronomy tube. The tube is for feeding, since she’d refused to eat for the past seven months. It is also for the 33 doses of medications per day we were sent home with to keep our baby girl alive...

The excerpt above is from a fundraising letter Denice Flerchinger is preparing to send. Mark and Denice Flerchinger have been married 12 1/2 years and live in Clarkston, Washington with their three daughters—Nichole (11), Catherine (10), and Tina (2 1/2 with cystinosis). Tina also has a rare disorder in the chiropractic field, anterior occiput, and sees a children’s chiropractor for this. Tina has had chronic ear infections and ruptured eardrums. Her pediatrician says her ear infections stem from vomiting because the fluid drains back into her passages.

Tina’s profuse vomiting, upset stomach, and lack of sleep have been very difficult for her. She was happier and had more energy after her medicine was regulated, but there are still challenges. The whole family is affected by the 24/7 feedings, medications, diaper changes, etc. How do they cope?

“Everybody helps out—whether it’s giving meds, starting and ending her feed, changing her always full diaper, or cleaning up vomit. Tina has a schedule, and everybody knows what it is! Dad and older sisters are a fabulous help!” says Denice Flerchinger.
The Flerchingers spend a lot of money on 3-ply overnight diapers and bladder control pads, which hold 12 oz. each. Tina drinks on average two gallons of water per day. She will easily drink 40 ounces of water at night.

"We usually get up 3-4 times nightly--refill bottles, change bedding, clothing & diapers, and give medications," says Denice, "This is my greatest challenge—lack of sleep. It also makes the potty training a bit difficult. Tina has constant urination because she is constantly thirsty and constantly drinking--due to her leaking kidneys."

Every day is a new day with Tina. Winter is very challenging with her low immune system. It seems she vomits a lot more and has constant fevers. A 24 hour flu will last two weeks for Tina. Because of her vomiting, she doesn’t get her meds entirely and that presents many problems. Another challenge Tina faces is that her g-tube is constantly infected.

Despite Tina’s challenges, she has been able to attend playschool usually one morning a week. This has helped her show an interest in food. Tina’s health is stabilized but does has its ups and downs.

“Now that Tina is maintaining her health, the biggest challenge is the two-year old attitude. It’s hard when you have a sick child because they don’t get the discipline the other children get because she is sick all the time,” says Denice.

The Flerchingers are active in the CRN online support group and attended the CRN Family and Medical Conference in Utah last July. The support group and conference helped them understand the long term effects of cystinosis, especially if not given the proper intervention. They have also helped them understand that they can have a somewhat “normal” life in the midst of cystinosis. The Flerchingers are always curious to hear how adults with cystinosis are doing, especially after transplant. They want to know how things will change for Tina.

Although the Flerchingers are still in the beginning stages of their journey with cystinosis, they have learned a lot by asking questions and doing research. Denice Flerchinger offers advice to other parents, “Be your child’s advocate. Use your instincts and ask a lot of questions. Be sure search out what is best for your child. Give Cystagon every six hours for the best long term results.”

Mark and Denice Flerchinger’s hope for Tina’s future is that a cure or better treatment for cystinosis is found so that she can live a “normal” life.

“She is a very special child. She loves life. She is very independent and strong willed. She’s a very happy child. She’s cute and has a sneaky way about her,” says Mark Flerchinger.

Denice added, “When Tina was diagnosed, we thought she would die. We were crushed. We thought we could never manage all her treatments, and now she is doing so well. It’s worth everything to see her thriving so beautifully.”

“This is just another chapter in life. It has brought our family closer together, and we know it is all a part of God’s plan.”
Tina and other children with cystinosis receive many syringes of medicine each day to keep them alive.

### Tina’s Daily Medicine and Supplement Routine

<table>
<thead>
<tr>
<th>Time</th>
<th>Medicine Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00am</td>
<td>Calciferol, Reglan, and Carnitine by mouth</td>
</tr>
<tr>
<td>9:00am</td>
<td>Bag of feed (Nutren Jr., Phosphosoda, Potassium Chloride, and Polycitra)</td>
</tr>
<tr>
<td>9:30am</td>
<td>Cystagon</td>
</tr>
<tr>
<td>3:00pm</td>
<td>Reglan and Carnitine by mouth</td>
</tr>
<tr>
<td>3:30pm</td>
<td>Bolus feed 2 oz. Nutren Jr. w/ Phosphosoda, Potassium Chloride, Polycitra, and Cystagon</td>
</tr>
<tr>
<td>9:30pm</td>
<td>Bolus feed 2 oz. Nutren Jr. w/ Phosphosoda, Potassium Chloride, Polycitra, and Cystagon</td>
</tr>
<tr>
<td>3:00am</td>
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</tr>
</tbody>
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“Be your child’s advocate. Use your instincts and ask a lot of questions. Be sure to search out what is best for your child. Give Cystagon every six hours for the best long term results.”

—Denice Flerchinger
Tina’s Eating Habits

Old Eating Habits:

Two-year-old Tina Flerchinger didn’t show a desire to eat for over a year. She would vomit at the sight of food but has gotten over that. On the rare occasion that she would eat, it would be cheese/cracker combos (just the cheese part), thin sliced turkey lunch meat, and tomato soup (fattened with half and half).

New Eating Habits:

She ate an entire chicken breast one night (rolled in yogurt, cracker crumbs, and parmesan cheese). Mark and Denice were shocked! From that point on they lowered her volume of feeds by half. She has started eating a bigger variety and will even say “hungry, hungry.” She gets in the fridge and shows interest in eating. She will never eat in the morning but will nibble in the afternoon and eat something big before bedtime.

“When Tina was diagnosed, we thought she would die. We were crushed. We thought we could never manage all her treatments, and now she is doing so well. It’s worth everything to see her thriving so beautifully.”

—Denice Flerchinger

“She is a very special child. She loves life. She is very independent and strong willed. She’s a very happy child. She’s cute and has a sneaky way about her.”

—Mark Flerchinger

Tina, Mark, Catherine, and Nichole Flerchinger at Disneyland with Minnie Mouse
Focus on Families—The Flerchinger Family

Continued from page 29

Hello,

My name is Catherine. I am 9. My sister has cystinosis. So we earned money by feeding animals and watering plants all summer. I hope we find a cure to cystinosis. My sister is only 2 and was diagnosed when she was 18 months old. She is eating pretty good. She loves cheese and turkey. But she only eats while watching a movie (It distracts her). Well, I have to go. BYE!

—Catherine Flerchinger

Nichole, Tina, and Catherine Flerchinger—Nichole and Catherine donated $88 they earned to the CRN!

Hello,

My name is Nichole. I am 10 years old. My sister Tina is 2 and has cystinosis. I earned some money by feeding a dog a few times and watering plants all summer. I decided I would use that money to help find a cure to cystinosis.

Love,

Nichole Flerchinger

P.S. I want to be a cystinosis doctor when I grow up.
Advice From Adults with Cystinosis

My name is Edward C. Langley. I was born December 9, 1978 with cystinosis. My sister, Jennifer, was born April 21, 1972 and also had cystinosis. She passed away on February 23, 1983 at the age of ten. She was diagnosed with cystinosis before I was born, so I was tested for cystinosis before birth. The test came back negative. My parents thought I would be born a healthy baby boy. Thankfully, I was diagnosed not too far after birth.

I was planning on making this short and sweet, but I would leave out many truths, and no one would be able to understand or learn from my experiences. As we all know, medication becomes a part of life for a child with cystinosis at a very young age. Some of us start taking medicine before we are able to speak or even crawl if we are lucky enough to be diagnosed as an infant. I had the bitter pleasure of taking Cysteamine. One of my youngest memories was having a serious stare down with the awful green liquid beast of a medication. I would even recite, “through the lips, through the gums, watch out stomach here it comes” to prepare for the awful terrible tasting nightmare to come. Then, of course, afterwards, I had to get the courage to swallow what everyone would describe as hell. I would fight my body with all my soul not to vomit. This was a losing battle no matter how hard I would fight. Now close your eyes and put yourself as a 4 year old mind having to do this 4 times a day. This is one of the many things a child with cystinosis learns to deal with. A few years later I had to take a daily shot of Epogen and growth hormone and add many other medications to the daily list. I felt like a walking pharmacy.

My family moved to California where there were more resources to treat cystinosis. Thank-you to Dr. Malek, Polly Nelson and of course, Dr. Jerry Schneider for their passion and influence they have shared with me. With this great medical team, it was time to experience life. My parents have had a huge impact on how I choose to live my life and will continue to do so in the future. They treated me as any other child. They did not limit my activities and did not limit my friends.

When walking to the corner store my friends would want candy, I would choose the saltiest beef jerky there was! I would even slice raw potatoes and dust them with a ton of salt! The other kids thought this was weird but did not care. As we all know children are more understanding of differences in people and society before they are exposed to the cruelties of the world. Besides they have more important things to worry about, such as who is it, where to hide, and even who is going to be what super hero for the next wrestling match. As I grew older, my interest would change as would some of my friends. I would go through the motions of waking up, cleaning up from the night’s urination fest, taking meds, throwing up, going to school, and then doing it again the next day. When I was now old enough to walk to school, nothing changed except my friends that I walked with would show up early to allow me to stare-down my meds and throw up so we would not be late for class.

I was around 11 or 12 when kids started to become cruel. Kids would comment on how my breath smelled like old milk. They would ask why I didn’t brush my teeth and so on. This was very hard because the girls started to catch my eye. The bad breath and body odor that came with cysteamine did not help my confidence with the ladies. I was teased yes but not nearly as much as others. I would always have something smart to say and kids would back off. I actually become pretty popular but still I was terrified more than the average boy to talk to the girls because of the smell. I was almost ashamed. Breath Assure helped my breath but not really my confidence. I would still get sick and would be scared my breath would smell or if I would sweat during PE that the smell would cover my body again. This became a serious part of life.

Continued on page 32
Advice From Adults with Cystinosis

Continued from page 31

during a time when I was trying to develop social skills and getting ready to enter the work force. I was always involved in karate, baseball, and video games and loved to be around people. This helped me tremendously and my parents would always encourage me to do these things. I would always carry breath assure with me so if that spoiled milk comment would come my way, I would be ready.

When I was about 13 years old, I stopped wetting the bed. I was supposed to go to a special camp for kids with illnesses, but I refused to go because of the bed wetting problem. My parents explained this to the doctor, and he prescribed a nasal spray to help. I used it once and never wet the bed again. I forget the name of it, but I was so happy. I never got to go to camp, but I felt great because I didn’t wet the bed anymore. When someone would stay over, I did not have to hide my bed-wetting or worry about rumors being spread.

Around this time this time I also started to learn about poetry in school and help my mom cook. I learned how to make some things I would actually eat, so I didn’t have to drench everything in soy sauce! I still love to write poetry and cook. I had my first kidney transplant when I was 15 years old. After my transplant, I was on a very limited diet and of course, NO SALT!! I thought my life was over. I learned how to use fresh herbs and trained my pallet so to speak. Now I can barely stand salt, or at least how much I would eat before. Yes, I still like soy sauce every now and then (HAAA). Because of my love for cooking, I decided to go to culinary school, and I am now a chef.

Shortly after my transplant, the doctors decided that it would be better for me to reduce my cysteamine and not vomit all the time. They thought it was more harmful for my health to be sick all the time verses having a slightly higher cystine level. I missed a lot of high school due to headaches and vomiting.

My advice to parents is let your kids do as much as possible. Support them in their hobbies and friends. Let them do a variety of new things. Let them feel as normal as possible. Try to understand what they go through and try to come up with ideas to help them with some of the situations that are coming or that they are currently going through. If they don’t feel different and have self confidence, they can thrive in life. Medication will become a normal routine, and kids will be able to do this with their eyes closed.

I hope someone can relate to what I have said and/or that it will help with the hard times. The biggest thing I go through as an adult is how young I look to people. This does not bother me because of the confidence I have developed. I have adapted to certain experiences, and they get easier. I hope I have been somewhat helpful and everyone lives a long, healthy, happy life.

Eddie Langley before attending a rock concert  Eddie and his friends at his Culinary School graduation
CRN Scholarship Information

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

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

APPLICATION PROCEDURE:

Each applicant must submit:

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

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

Finalists may be interviewed before selections are made.

DEADLINE FOR APPLICATION: Application and all accompanying documents must be received at the Cystinosis Research Network office in a single, flat package postmarked by August 15, 2006. FAXES OR E-MAILS WILL NOT BE ACCEPTED.

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

MAIL APPLICATION PACKETS TO:

Sandy Glaize
4133 Conway Place Circle
Orlando, Florida 32812
Join The Cystinosis Research Network (CRN) and become part of a global network of caring families, concerned individuals and healthcare professionals working together in the fight against cystinosis. The Cystinosis Research Network’s vision is the discovery of improved treatments and ultimately a cure for cystinosis. The CRN is an all-volunteer; non-profit organization dedicated to sponsor and advocate research, provide family support, and educate the public and medical communities about cystinosis. The CRN funds research and programs primarily through donations from the public, grassroots fundraising events and grants.

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

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

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

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

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

Joining the Cystinosis Research Network enables you to:

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

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

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

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

Join the Cystinosis Research Network today!

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

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

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

Please complete the form & mail with check payable to CRN to: CRN, 10 Pine Avenue, Burlington, MA 01803.

Name___________________________________________________________
Street____________________________________________________________________________________
City & State_________________________________________ Zip Code__________ Country __________
Phone__________________________ Fax_______________________Email_____________________________

Name of Child / Adult / Acquaintance / Patient affected with cystinosis: _________________________________

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

I am interested in joining a committee to help CRN. Please check: _______Yes ________No
If yes, please check the committee you would like to join or would like more information about:

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

For more information, please call CRN at 1-866-276-3669, 781-229-6182 or email crn@cystinosis.org or visit www.cystinosis.org. Thank You!

Join A CRN Support Group

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

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

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

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

- **The CRN News Group** is for all who would like to receive announcements of upcoming events, important activities and breakthroughs.
Please Help CRN In Our Mission of Finding A Cure and Improved Treatments, Providing Family Support, and Raising Awareness

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

Enclosed is my tax deductible contribution of: $__________________ made payable to the Cystinosis Research Network (CRN) and mail to: 10 Pine Avenue, Burlington, MA 01803

Name____________________________________________________________________________________

Street__________________________________________________________________________________

City & State___________________________________ Zip Code____________________________________

Phone_________________________ Fax_______________________ Email____________________________

In Honor Of________________________________________________________________________________

In Memory Of______________________________________________________________________________

You may send notification of my gift to:

_________________________________________________________________________________________

United Way and You

The United Way begins its annual fundraising drive each fall in nearly every community in the United States. It provides a way for many charities to obtain funds by individuals contributing a small portion of their paycheck through payroll deduction. Each United Way chapter lists a variety of organizations that may be chosen for payroll deductions, most of which are locally based. The majority of United Way chapters allow individuals to write in the charity of their choice. Even though we are a national organization, our 501(c)(3) nonprofit status qualifies us for this write-in option. CRN’s Federal Tax ID # is: 04-3323789.

To initiate a write-in campaign in your workplace, contact your company’s United Way chairperson to ask if there is a write-in option and if so, the possibility of informing the rest of the employees about the special needs of cystinosis research. Most coworkers are eager to donate to a cause that is personally tied to a colleague. Posting a public letter or a poster asking your fellow employees to join you in our fight against cystinosis might be one way to reach all the employees and increase our funding. If you or your United Way chairperson has any questions, please call CRN at toll free: 1-866-276-3669 or 781-229-6182.

Donation Reminders

• Don’t forget you can donate online through Network for Good. Visit www.cystinosis.org for more information.

• Don’t forget about your company’s matching-gift programs.

Any gift, large or small, is greatly appreciated!
The Cystinosis Research Network expresses its gratitude for donations, memorial gifts, and “in your honor” gifts. Thanks to all for giving a gift that continues to give. With the financial support of members and friends, the Cystinosis Research Network continues our mission of supporting cystinosis research, cystinosis education programs, and providing family support. We wish to thank the following individuals and groups whose donations were received between August 1, 2005 and May 22, 2006.

**Correction:** Alyson and Patrick Ryan were mistakenly omitted from the donor listing of the Fall 2005 newsletter. Alyson and Patrick generously donated $150 in honor of Jack Greeley. The Ryan’s also doubled their generosity with a matching gift from the American Express Foundation.

**Miracle Workers - $84,000**
Eastside High School in honor of Laura McGinnis

**Leadership Circle ($5,000 - $15,000)**
Richard and Diane Azar in honor of John Ben and Ava Shepperd
The Rudolf and Ruth Eschbach Family Fund

Jose and Velyna Morales through United Way of New York City in honor of Christian Morales
Mr. and Mrs. Seay in honor of John Ben and Ava Shepperd
Sigma Tau Pharmaceuticals, INC
Amy Stieren in honor of John Ben and Ava Shepperd

**Ambassadors ($2,500 - $4,999)**
Cystinosis Research Foundation in honor of Natalie Stack for SRB
Timothy and Alissa Horrigan in honor of Jack Greeley's 6th birthday
Dahn Maier through United Way of New York City in honor of Christian Morales
Amy Shelton McNutt Charitable Trust in honor of John Ben and Ava Shepperd
Tamarack Family Fun Day in honor of Jack Greeley
Sharon Turney through the United Way of Central Ohio in honor of Christian Morales

**Benefactors ($1,000 - $2,499)**
Thomas and Julia Arndorfer in honor of Jack Greeley
Breanne, INC in honor of Jack Greeley
Chan and Hillary Conrey in honor of John Ben and Ava Shepperd
Tom and Jennifer Conway in honor of Jack Greeley
Mario Diana, MD in honor of John Ben and Ava Shepperd

Walter and Gayle Embrey in honor of John Ben and Ava Shepperd
Genesco Sports Enterprises in honor of Jack Greeley's 6th birthday
Gorton's Gift Matching Program Matching Gift of Larry LeBeau in honor of Evan and Alexis LeBeau
Robert and Mark Hancock in honor of Jack Greeley's 6th birthday
Dan and Jan Julian – Texas Hold 'Em Fundraiser in honor of Kenadee Julian
Grandma and Grandpa Julian in honor of Kenadee Julian's 3rd birthday
Alan Kaplan in honor of Jack Greeley - Tamarack Family Fun Day
Peter and Laura Karmanos in honor of Jack Greeley's 6th birthday
Lawrence and Patricia LeBeau in honor of Evan and Alexis LeBeau
 Mildred McFelea in honor of Brittney, Robert and Sammy Carroll
Panson Electrical Services
John Ben Shepperd Estate in honor of John Ben and Ava Shepperd
Kim and John Shepperd in honor of John Ben and Ava Shepperd
Mamie S. Shepperd in honor of John Ben and Ava Shepperd
Jeff and Nancy Stack in honor of Natalie Stack
United Way of Greenville County in honor of John Ben and Ava Shepperd
Tamarack Family Fun Day in honor of John Ben and Ava Shepperd
Sharon Turney through the United Way of Central Ohio in honor of Christian Morales

**Sponsors ($500 – $999)**
Attwater Blue Corp in honor of Jack Greeley's 6th birthday
BP Foundation in honor of Jack Greeley - Matching James Dempsey Gift
James and Lisa Dempsey in honor of Jack Greeley's 6th birthday
Len and Pam Dillon in honor of Jack Greeley's 6th birthday
Terive and Debra Duperier, MD in honor of John Ben and Ava Shepperd
Mark and Denice Flerchinger in honor of Tina Flerchinger

**Patrons ($250 – 499)**
Pauly Acura in honor of Jack Greeley
Bank of America Foundation matching gifts of Kim Morander and Debra Ponce De Leon
Chad Burmeister, DMD, PC Texas Hold ‘Em fundraiser in honor of Kenadee Reese Julian
Angela Christie in honor of Jack Greeley's 6th Birthday
Candes Chumney in honor of John Ben and Ava Shepperd
Victoria Chumney in honor of John Ben and Ava Shepperd
Dana Dressler in honor of Jack Greeley's 6th Birthday
Lisa Dvorak in honor of Jack Greeley - Tamarack Family Fun Day
Lisa Dvorak in honor of Jack Greeley's 6th Birthday
Anne Eardley in honor of Jack Greeley's 6th birthday
Michael Eardley in honor of Jack Greeley
Jane and James Saccaro in honor of Heidi Hughes
Chris and Tracie Shepard in honor of Jack Greeley's 6th birthday
Thomas Shine in honor of Jack Greeley's 6th birthday
David Sliwicki in honor of Jack Greeley - Tamarack Family Fun Day
Elva Smith in honor of Mitchell Smith
The Northstar Group in honor of Jack Greeley's 6th birthday
Western Community Bank in memory of Sierra Woodward

**Corrections:**
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Bill and Maria Flannery in honor of Jack Greeley's 6th Birthday
Matthew Geary in honor of Alex Weaver - 10K Race
Steven and Sandra Gehrke in honor of Jack Greeley - Tamarack Family Fun Day and in honor of Jack Greeley's 6th birthday
Goff and Anthony, PLC in honor of Alex Weaver - 10K Race
Stephen Hundley through United Way of Los Angeles in honor of Christian Morales
David Inglis in honor of John Ben and Ava Shepperd
Patricia Jette in honor of Jack Greeley's 6th Birthday
Carl and Brenda Johnson in honor of Alex Weaver - 10K Race
Dr. Rick and Mrs. Phyllis Kaskel
Christopher and Debra Kiah in honor of Jack Greeley
Dr. Rick and Mrs. Phyllis Kaskel
American Express Foundation Matching Gift Program Matching Gift of Alison Ryan in honor of Jack Greeley
Andrea and Courtland Anderson in honor of Jack Greeley's 6th birthday
Carolyn and Donald Anderson in memory of Darlene Ritter
Anonymous in honor of Ellie and Hugh Mandrell
Richard and Patricia Arndt in honor of Jack Greeley
The Joe Barfield Group in honor of John Ben and Ava Shepperd
Christopher and August Bain in honor of Alex Weaver - 10K Race
The Joe Barfield Group in honor of John Ben and Ava Shepperd
David Inglish in honor of John Ben and Ava Shepperd
Alex Weaver - 10K Race
Carl Bassewitz in honor of Jack Greeley
Joyce E. Silver Reit Management & Research LLC
Rental Max, LLC in honor of Jack Greeley's 6th Birthday
Marcia Resnick in honor of Jack Greeley's 6th Birthday
Pamela and Jeffrey Roesler in honor of Pam Roesler's retirement and in honor of Kenadee Julian
St. Paul's Mission Church
William and Roxanne Schneider in honor of Jack Greeley's 6th Birthday
Seaver Marketing Group in honor of Jack Greeley's 6th Birthday
Alfred and Honey Shepperd in honor of John Ben and Ava Shepperd
Jason and Jennifer Stavros in honor of Jack Greeley
Kenneth and Barbara Anne Stephens in honor of John Ben and Ava Shepperd
George Stieren in honor of John Ben and Ava Shepperd
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Thad Ziegler in honor of John Ben and Ava Shepperd
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Sally and Gary Messner in honor of Kellen Binger
Jeffrey and Kim Morander in honor of Jack Greeley
Marianne Morse in honor of John Ben and Ava Shepperd
Pauly Motors in honor of Jack Greeley - Tamarack Family Fun Day Plains Capital Bank in honor of John Ben and Ava Shepperd
Joyce E. Silver Reit Management & Research LLC
Rental Max, LLC in honor of Jack Greeley's 6th Birthday
Margaret O'Connor in honor of Jack Greeley's 6th Birthday
Marcia Resnick in honor of Jack Greeley's 6th Birthday
Pamela and Jeffrey Roesler in honor of Pam Roesler's retirement and in honor of Kenadee Julian
St. Paul's Mission Church
William and Roxanne Schneider in honor of Jack Greeley's 6th Birthday

Peter Bowen
David Branch in honor of Alex Weaver - 10K Race
Richard and Elizabeth Brandt in honor of Jack Greeley's 6th Birthday
Lori Brown in honor of Steve Schleuder
Matt and Courtney Burkholder in honor of John Ben and Ava Shepperd
Campbell and Campbell, PC in honor of Alex Weaver - 10K Race
Jim and Debra Carabin in honor of Jack Greeley's 6th birthday
Paul and Becky Carlisle in honor of Jack Greeley's 6th birthday
Vince and Linda Cicero in honor of Jack Greeley's 6th birthday
Chucker and Reiback Attorneys and Counselors at Law in honor of Jack Greeley's 6th birthday
Montgomery and Colleen Cornell in honor of Jack Greeley's 6th birthday
Edward and Laura Cramer in honor of Jack Greeley's 6th birthday
Craig Cooley, Attorney at Law in honor of Alex Weaver - 10K Race
John Cordova in honor of Jack Greeley's 6th birthday
Jacqueline and Christopher Curtis in honor of Jack Greeley's 6th birthday
Gerald and Elaine Daley in honor of Heidi Hughes
Patti and Vincent Darmali in honor of Jack Greeley - Tamarack Family Fun Day
DC Sports and Sponsorship in honor of Jack Greeley's 6th birthday
Christopher and Karen Dekker in honor of Jack Greeley's 6th birthday
Jeff and Aimee Devlin in honor of Jack Greeley's 6th birthday
Pamela Dillon in honor of Jack Greeley and all children with cystinosis
Gary and Mary DiSanto- Rose in honor of Laura Krumenacker
Brian Doughty in honor of Jack Greeley's 6th birthday
Sarah Dressler in honor of Jack Greeley's 6th birthday
Russell and Myrtle Duffin in honor of John Ben and Ava Shepperd
Carol Dunbar in honor of Whitney Glaize
Lori Duncan in honor of Bettie Lee Loefstrom
Randy and Marcia Elkin in honor of Jack Greeley's 6th birthday
Lynnette Embrey in honor of Roxanna and Carlos Rosado
Clyde Emrich in honor of Jack Greeley's 6th birthday
Gretchen Erwin in honor of the Aults and Mary Ann Hester
J. Michael Estes in honor of Alex Weaver - 10K Race
Carolyn and Donald Anderson in memory of Darlene Ritter
Anonymous in honor of Ellie and Hugh Mandrell
Richard and Patricia Arndt in honor of Jack Greeley
The Joe Barfield Group in honor of John Ben and Ava Shepperd
Danny and Katherine Farnham in honor of Pam Roesler's retirement and in honor of Kenadee Julian
Janice and David Feder in honor of Jack Greeley's 6th birthday
Christopher Fetta in honor of Laura Krumenacker
Arthur and Patricia Filete in honor of Laura Krumenacker
Thomas and Lisa Finks in honor of Jack Greeley's 6th birthday
Gerry and Nancy Finn in honor of Janice Finn
Five Star Sports Frankie and Marnelle Flowers in honor of Jack Greeley
Jake and Janet Frego in honor of Jack Greeley
Cheri and Matt Friend in memory of Sierra Woodward
The Frye Family in honor of Paula Shal
Michael and Tracy Fillion in honor of Jack Greeley's 6th birthday
Robert and Gretchen Funck in honor of Jack Greeley - Tamarack Family Fun Day
David Gammino in honor of Alex Weaver - 10K Race
Stacy Garrett, III, Attorney at Law in honor of Alex Weaver - 10K Race
General Sports and Entertainment in honor of Jack Greeley's 6th Birthday
Jeff Greenbury in honor of Jack Greeley's 6th Birthday
Grover Consulting LTD in honor of Jack Greeley's 6th Birthday
Harry Hagy, Jr. in honor of Jack Greeley's 6th Birthday
George and Denise Hefner, MD in honor of Jack Greeley's 6th Birthday
Michael and Wendy Herst in honor of Jack Greeley's 6th Birthday
Mr. and Mrs. Roger Hill, Jr. in honor of John Ben and Ava Shepperd
Brenda and Michael Hyyoung Janus
Greg and Susanne Immell in honor of Jack Greeley's 6th Birthday
Julie and Gene Inderrieden in memory of Henry Schnabel and in honor of Joseph Jordan
Murray Janus in honor of Alex Weaver - 10K Race
Jefferson State Bank in honor of John Ben and Ava Shepperd
Patricia Jette in honor of Jack Greeley - Tamarack Family Fun Day
Jeffrey and Carolyn Joniak in honor of Jack Greeley's 6th Birthday
Richard and Mary Jordan in memory of Henry Schnabel and in honor of Joseph Jordan
Kaesner and Associates in honor of Alex Weaver - 10K Race
Alfonso Lapelusa, DDS in honor of Jack Greeley's 6th Birthday
Jodi Kirsh in honor of Jack Greeley - Tamarack Family Fun Day
Douglas and Amy Klein
Ivan and Kathleen Knezevic in honor of Jack Greeley's 6th Birthday
Alfonso Lapelusa, DDS in honor of Jack Greeley's 6th Birthday
Leanne Larson in honor of Jack Greeley and Gerald Larson in honor of Jack Greeley - Tamarack Family Fun Day
Diana and Robert Laskowski in honor of Jack Greeley's 6th Birthday
Gerard and Colleen Leider in honor of Jack Greeley - Tamarack Family Fun Day
Mark and Mindy Leonard in honor of Jack Greeley's 6th Birthday
T Leopold in honor of John Ben and Ava Shepperd
Philip and Reshmi Lisitza in honor of Jack Greeley - Tamarack Family Fun Day
Lone Star Medical Equipment in honor of John Ben and Ava Shepperd
Jed and Nancy Maebius in honor of John Ben and Ava Shepperd
Joseph Massie III in honor of John Ben and Ava Shepperd
Robert and Karen May in honor of Jack Greeley - Tamarack Family Fun Day
Ray and Pauline McCharen in honor of John Ben and Ava Shepperd
Gary McIntosh, CPA in honor of John Ben and Ava Shepperd
Suzanne McIntosh in honor of John Ben and Ava Shepperd
Melodie McClurren in honor of John Ben and Ava Shepperd
Scott and Carol McKeon in honor of Traci Hammond
Medieval Castle in honor of John Ben and Ava Shepperd
Judith Meguire in honor of Jack Greeley's 6th Birthday
Susan Membrino in honor of Jack Greeley's 6th Birthday
Laura and Lewis Moorman in honor of John Ben and Ava Shepperd
Raymond and Linda Moreno in honor of Ray Moreno Jr.
Anthony and Maureen Nasrallah in honor of Jack Greeley's 6th Birthday
Jennifer Newman, P.C. in honor of Alex Weaver - 10K Race
John Owen
James and Amelia Padgitt in honor of Jack Greeley's 6th birthday
David and Juliette Peart in honor of Jack Greeley's 6th birthday
Perna in honor of Jack Greeley's 6th birthday
Daniel and Linda Pinsel in honor of Jack Greeley's 6th birthday
Beth and Chris Poteet in honor of Jack Greeley's 6th birthday
Gail and Jack Potts in memory of Lynn Potts
David Proper in honor of Jack Greeley's 6th birthday
Richard and Jamie Reider in honor of Jack Greeley's 6th birthday
Rice, Everhart and Baber in honor of Alex Weaver - 10K Race
Craig and Jan Riesch in honor of Bailey Riesch
Philip Riley
John and Doreen Zanotelli in honor of Jack Greeley - Tamarack Family Fun Day
Allison and Joshua Zeller in honor of John Ben and Ava Shepperd

**Contributors (50 - $99)**
A Better Way Chiropractic in honor of Laura McGinnis / Belk Fundraiser
Stephen Acampora in honor of Jack Greeley's 6th Birthday
Mathew and Carolyn Adler in honor of Jack Greeley - Tamarack Family Fun Day
Altia Group, INC in honor of Jack Greeley
Lorraine Argo in honor of Jack Greeley's 6th Birthday
Raymond and Nancy Arndt in honor of Jack Greeley
William and Jennifer Axelsen in honor of Jack Greeley - Tamarack Family Fun Day
John Babcock in memory of Mark Stetson
Joe Barfield in honor of John Ben and Ava Shepperd
Richard and Leigh Benowitz in honor of Shea Hammond
Samuel and Karen Bloodgood in honor of Jack Greeley's 6th Birthday
Judy Busse in honor of Laura McGinnis
Mary and Bob Canha in memory of Mark Stetson
Gregory Carney in honor of Jack Greeley's 6th Birthday
Ramon Chalkley in honor of Alex Weaver - 10K Race
Michael and Lauren Chocholak in honor of Jack Greeley's 6th Birthday
Cynthia Churches in honor of Jack Greeley's 6th Birthday
Rosemary Conard in memory of Michael Frederick Conard
Bernard and Roberta Coniglio in honor of Jack Greeley - Tamarack Family Fun Day
Margaret and Eric Deglau in honor of Alex Weaver - 10K Race
Barbara and James Dolan in honor of Alex Weaver - 10K Race
James Dvorak in honor of Jack Greeley - Tamarack Family Fun Day
Roberta Dykes in memory of Eugene McFelea
Alice and Larry Emmons in honor of Jack Greeley's 6th Birthday
Patricia Ernstrom in honor of Jack Greeley's 6th Birthday

Christine and Kevin Feil in honor of Jack Greeley - Tamarack Family Fun Day
Brenda Ferber in honor of Jack Greeley's 6th Birthday
Nicholet and Catherine Flerchinger in honor of Tina Flerchinger
Julie Galassini in honor of Jack Greeley - Tamarack Family Fun Day and Jack's 6th Birthday
Alicia Gass in honor of Jack Greeley
Susan Geary in honor of Alex Weaver - 10K Race
Diane Gillis in honor of Jack Greeley's 6th Birthday
Gordon and Margaret Glade, MD in honor of Tahnie Woodward
Darlene Godsey in honor of Mitchell Smith
Harriet and Barry Goldberg in honor of Jack Greeley - Tamarack Family Fun Day and Jack's 6th birthday
Jamie Goldberg in honor of Jack Greeley - Tamarack Family Fun Day
Dr. Sandra Goldberg in honor of Jack Greeley's 6th Birthday
Gary and Kathryn Gordon in honor of Jack Greeley
Rachel Greisman in honor of Jack Greeley's 6th Birthday
David and Carolyn Griffith in honor of Jack Greeley's 6th Birthday
Caroline Guip in honor of Jack Greeley's 6th Birthday
Angelina Haff in honor of John Ben and Ava Shepperd
Colleen and Jack Hammond in honor of Shea Hammond and in memory of Mark Stetson
Anna and George Haschert in honor of Kenadee Julian
Melissa Heilman and Family in honor of Kellen Binger
Kenneth and Geraldine Heinemeyer in honor of Cody Becht
Paige Holland in honor of John Ben and Ava Shepperd
Michael Huberman in honor of Alex Weaver - 10K Race
Dan and Jan Julian Texas Hold 'Em fundraiser in honor of Kenadee Reese Julian
Catherine and Peter Kanaris in honor of Jack Greeley - Tamarack Family Fun Day
Garrin and Julie Kapecki in honor of Jack Greeley's 6th Birthday
Marty and Amy Kaplan in honor of Jack Greeley - Tamarack Family Fun Day
Jeffrey and Joanna King in honor of Jack Greeley's 6th Birthday

Phyllis Ross in honor of Alex Weaver and in honor of J. Edward Penn
Heather Russo in honor of John Ben and Ava Shepperd
Alison and Patrick Ryan in honor of Jack Greeley's 6th birthday
Heather and Carlos Salazar in honor of Jack Greeley
Kelly Satel in honor of John Ben and Ava Shepperd
Carl and Terri Schleuder in memory of Sierra Woodward
Frates and Josephine Seeligson in honor of John Ben and Ava Shepperd
David and Kristin Sliwicki in honor of John Ben and Ava Shepperd
Frates and Josephine Seeligson in honor of John Ben and Ava Shepperd
David and Kristin Sliwicki in honor of John Ben and Ava Shepperd

Thigpen
Two Point Conversions in honor of Jack Greeley - Tamarack Family Fun Day
Ukrop's Super Markets in honor of Alex Weaver
United Way of Allegheny County – Kristen Martin
United Way of Piedmont
Elizabeth Urrutia in honor of John Ben and Ava Shepperd
Lesa Vidovek in honor of Jack Greeley's 6th birthday
Dr. and Mrs. James Waters in honor of Jack Kitchens 6th Birthday
Robert Weiland in honor of Jack Greeley - Tamarack Family Fun Day
Dean and Jody Weinberg in honor of Jack Greeley's 6th Birthday
David Whaley, Attorney at Law, in honor of Alex Weaver - 10K Race
Andrew and Cheryl Wood in honor of Alex Weaver - 10K Race
Denise and Jerry Woodward in memory of Sierra Woodward
Chris and Holly Yates in honor of John Ben and Ava Shepperd
The Zahora Family in honor of Shea Hammond
John and Doreen Zanotelli in honor of Jack Greeley's 6th Birthday

The Cystinosis Research Network - Spring/Summer 2006
Allen and Jodi Kirsh in honor of Jack Greeley’s 6th Birthday
Wade Kizer in honor of Alex Weaver - 10K Race
Douglas and Amy Klein in honor of Jack Greeley
Marvin and Roberta Klopfstad in memory of Tosh Tanemura, Elsie Zeven Bergen and Paul Nix
Nicole, Molly, Lucy and Luke Kollman in honor of Kellen Binger
Jacquelyn Kovich in honor of the Thoen- sen Family for their generosity and kindness
Scott and Cheryl Landau in honor of Jack Greeley’s 6th Birthday
Sarah Lennemaruer in honor of John Ben and Ava Shepperd
Kelly Lewis in honor of Alex Weaver
Bruce and Susan Malter in honor of Jack Greeley
Kathryn Martinez in honor of John Ben and Ava Shepperd
Mettlel Children’s Foundation Matching
Paula Shal gift
Michael and Amy McClure in honor of Jack Greeley
John McGarvey in honor of Alex Weaver - 10K Race
JT and Frankie McGinnis in honor of Laura McGinnis / Belk Fundraiser
James and Janet McKeown in honor of Jack Greeley
Kevin and Mary Lee McMahon in honor of John Ben and Ava Shepperd
Marilyn and William Moll in honor of John Ben and Ava Shepperd
Anthony Montalto in honor of Jack Greeley’s 6th Birthday
Eric Moses in honor of John Ben and Ava Shepperd
Michael and Julie Muth in honor of Jack Greeley’s 6th Birthday
Katherine Nagle in honor of Jack Greeley’s 6th Birthday
Charles and Julianne Niehaus in honor of Pam Roessler’s retirement and in honor of Kenadee Julian
Patricia and Edward Olsson in honor of Laura Krummenacker
Catherine Park in honor of John Ben and Ava Shepperd
Annamaria Petitti in honor of Jack Greeley’s 6th birthday
Steven Tamarack in honor of Jack Greeley - Tamarack Family Fun Day
Dennis and Kerry Prado in honor of Jack Greeley - Tamarack Family Fun Day
Raul and Lucy Prado in honor of Christian Morales
Katherine Purviance in honor of Traci Hammond
Jeffrey and Patricia Rayner in honor of Kellen Binger
Duncan Reid in honor of Alex Weaver - 10K Race
Mark and Lisa Reposa in memory of Mark Stetson
Andrea Reyes in honor of Laura McGinnis / Belk Fundraiser
Richmond Criminal Law in honor of Alex Weaver - 10K Race
David and Suzanne Ritter in honor of Jack Greeley - Tamarack Family Fun Day
Elizabeth Rosado in honor of John Ben and Ava Shepperd
Phyllis Ross in honor of Patricia McCaffrey’s birthday and in honor of Alex Weaver
Cynthia Roth in honor of Alex Weaver - 10K Race
M.L. Rowe in honor of Alex Weaver - 10K Race
Paula and Laura Russo in honor of Jack Greeley
Anne Ryan in honor of Jack Greeley
Stephen and Tracy Ryan in honor of Jack Greeley’s 6th birthday
S7 Ranch in honor of John Ben and Ava Shepperd
Aaron and Suzanne Siegel, MD in honor of Jack Greeley’s 6th birthday
David and Kristin Sliwicki in honor of Jack Greeley
Carol Smyth in honor of Shea Hammond
Linda and Glenn Spungen in honor of Jack Greeley - Tamarack Family Fun Day
David Stock in honor of Alex Weaver - 10K Race
George and Marjorie Tattersfield in honor of Jack Greeley’s 6th Birthday
Ben and Theresa Thigpen in honor of Julie Thigpen and Morgan Friend’s Birthdays
Elizabeth Tilley in honor of John Ben and Ava Shepperd
Amy Turner in honor of Alex Weaver - 10K Race
Jeffrey and Kimberley Urban in honor of Jack Greeley
Mary Waters in memory of Gene McFelea
Russell and Ann Waters in memory of Gene McFelea
Marvin and Roxie Weber in honor of Jack Greeley’s 6th Birthday
David Wells in honor of Jack Greeley’s 6th Birthday
Lawrence Wert in honor of Jack Greeley’s 6th Birthday
Witmeyer and Allen in honor of Alex Weaver - 10K Race
John and Doreen Zanotelli in honor of Jack Greeley

Friends (up to $49)
Stephen Acampora in honor of Jack Greeley - Tamarack Family Fun Day
Ruth Albrecht in honor of Jack Greeley - Tamarack Family Fun Day
Altria Group, INC Matching donation of Anne G. Ryan
American Charities Distribution Account
Ali and Lori Amirshahi in honor of Alex Weaver - 10K Race
Leonard and Beverly Andrews in honor of Laura McGinnis / Belk Fundraiser
Anonymous through United Way of Piedmont in honor of Laura McGinnis
Anonymous in honor of Jack Greeley
Anonymous in honor of Kellen Binger
William and Jennifer Axelsen
Douglas and Lisa Ayers in honor of Jack Greeley
Debra and Howard Baker in honor of Jack Greeley - Tamarack Family Fun Day
Elliott Bender, Attorney at Law in honor of Alex Weaver - 10K Race
John and Brit Bending in honor of Jack Greeley’s 6th birthday
Mindy and David Bennett in honor of Jack Greeley - Tamarack Family Fun Day
Robert and Helen Berland in honor of Jack Greeley - Tamarack Family Fun Day
Marjorie Bonnell in honor of Shea Hammond
Anthony and Tracy Boone in honor of Alex Weaver - 10K Race
Marjolein Bos in honor of Mark Bos
Elizabeth and Richard Brandt in honor of Jack Greeley
Shannon Burghart in honor of John Ben and Ava Shepperd
Traci Cannada in honor of Alex Weaver - 10K Race
C.E. and Karen Cantrell in honor of John Ben and Ava Shepperd
Claire Cardwell in honor of Alex Weaver - 10K Race
Wesley and Margaret Carter in honor of Traci Hammond
Jennifer Cason in honor of Laura McGinnis / Belk Fundraiser
Chain of Lakes 4H Club, Kimberley Moon, in honor of Jack Greeley
Haein and Howard Chan in honor of Jack Greeley
Clara Cheney in honor of Alex Weaver - 10K Race
Stacy and Charles Cohen in honor of Jack Greeley
Cameron and Nicole Colvig in honor of Jack Greeley - Tamarack Family Fun Day
Thomas and Jennifer Conway in honor of Jack Greeley - Tamarack Family Fun Day
Amy Cook in honor of Jack Greeley - Tamarack Family Fun Day
Paige and John Cranor, III in honor of Alex Weaver - 10K Race
Paul and Ida Crimmins in honor of Jack Greeley's 6th birthday and in honor of Grace Goldberger's 9th birthday
Cathleen and Frank Crone in honor of Laura McGinnis / Belk Fundraiser
Michelle Crotty
Jerome and Margaret Crowley in honor of Jack Greeley - Tamarack Family Fun Day
Beverly and James Curry in honor of Alex Weaver - 10K Race
Paul Cushman in honor of Alex Weaver - 10K Race
Leontyne Dasch in honor of Jack Greeley's 6th birthday
Nancy Davis in honor of Shea Hammond and in memory of Dorothy Mills
Jeffrey and Angel Depew in honor of Jack Greeley
John and Kathleen Donovan in memory of Mark Stetson
Michael and Erin Downey in honor of Jack Greeley
John Dressler in honor of Jack Greeley's 6th birthday
John and Merribeth Driscoll in honor of Shea Hammond
Janice Dubell
Elsa Duenas
Stephen Dupee in honor of Jack Greeley's 6th birthday
Douglas and Kelly Dupont in honor of Jack Greeley - Tamarack Family Fun Day
Anna Durbin in memory of Henry Schnabel and in honor of Joseph Jordan
Nancy Dykes in honor of Laura McGinnis / Belk Fundraiser
Sam and Gail Eckerling in honor of Jack Greeley - Tamarack Family Fun Day
Dwight and Robin Ekenberg in honor of Jack Greeley
Randy and Marcia Elkin in honor of Jack Greeley
Saadia and Jean-Acard Fabien in honor of Jack Greeley
James and Monica Fairman in honor of Jack Greeley
Kay Fearnow in honor of Alex Weaver
Elizabeth Fetta in honor of Laura Krummenacker
Jennifer Findell in honor of Jack Kitchens Rudolf and Barbara Friedel in honor of Mr. and Mrs. Newmann
Cheri Friend in honor of Theresa Thigpen's Birthday
David and Shelley Frisch in honor of Jack Greeley
Kay Frye in honor of Alex Weaver - 10K Race
Joseph and Dorine Fusaro in honor of Traci Hammond
Steven and Lynn Gackenbach in honor of Jack Greeley - Tamarack Family Fun Day
Eric and Dena Gard in honor of Mikaela Gard
Diane Gillis in honor of Jack Greeley - Tamarack Family Fun Day
Deborah and Harry Goldsholl in honor of Jack Greeley's 6th birthday
Brian and Julie Goolsby in honor of Jack Greeley - Tamarack Family Fun Day
Carolyn Grady in honor of Alex Weaver - 10K Race
Jacob and Sharla Gray in honor of John Ben and Ava Shepperd
Carrie Green in honor of John Ben and Ava Shepperd
Robert Greisman in honor of Jack Greeley's 6th birthday
Grover Consulting LTD in honor of Jack Greeley - Tamarack Family Fun Day
Louise and Kyle Gunter in honor of John Ben and Ava Shepperd
Shauna Hall in memory of Sierra Woodward
Rusty and Vanessa Halloran in memory of Mark Stetson
Gregory and Sarah Harrigan in honor of Kellen Binger
Gregory and Robyn Hebard in honor of Jack Greeley
George and Denise Hefner, MD in honor of Jack Greeley - Tamarack Family Fun Day
Michael and Wendy Herst in honor of Jack Greeley
Gary Hicks in honor of Alex Weaver - 10K Race
Jennifer Hodson in memory of Mark Stetson
Paige Holland in honor of John Ben and Ava Shepperd
Cassandra and Ed Horvath in honor of Jack Greeley

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Ryan and Elizabeth Huzjak in honor of Jack Greeley's 6th birthday
Greg and Susanne Immell in honor of Jack Greeley
Gail Jackson in honor of Alex Weaver
Lynn and Jeff Joachim in memory of Joy Inglis
Carl and Brenda Johnson in honor of Alex Weaver - 10K Race
Douglas and Barbara Johnson in memory of Sierra Woodward
Ellen and Clay Johnson in honor of Laura McGinnis / Belk Fundraiser
Henny Johnson in memory of Sierra Woodward
Ryan and Susan Johnsson in honor of Tannah Woodward
Ann Jones in honor of Alex Weaver
Adrienne and Kevin Jordan in honor of Jack Greeley's 6th birthday
Iris Jordan in honor of Alex Weaver - 10K Race
Dan and Jan Julian in honor of Kenadee Julian
Huang Min Jun
Joseph and Mary Ellen Kadleck in honor of Jack Greeley - Tamarack Family Fun Day
Alexander and Marie Kaparos in honor of Jack Greeley's 6th birthday
Garrin and Julie Kapecki in honor of Jack Greeley
Alan and Michelle Kaplan in honor of Jack Greeley
Stanley and Elaine Kend in honor of Jack Greeley's 6th birthday
Paul and Ada Kinschererff in honor of Jack Greeley - Tamarack Family Fun Day
Allen and Jodi Kirsh in honor of Jack Greeley
Travis Kitchens in honor of Jack Kitchens 6th birthday
Sissy Kling in honor of Shea Hammond
Robert and Julie Lynn Koewler in honor of Jack Greeley's 6th birthday
Emily and Clyde Koon in honor of Alex Weaver - 10K Race
Darren and Jill Kramer in honor of Jack Greeley - Tamarack Family Fun Day
Jon Lawniczak in honor of Jack Greeley
Lynne and Brian Leary in memory of Mark Stetson
Brittney and Brett LeBeau in honor of Evan and Alexis LeBeau
Loveit Lemay in memory of Sierra Woodward
Laura Lewin in honor of Traci Hammond
Gale Livingston in honor of Alex Weaver - 10K Race
Roger and Dorothy Lord in honor of Jack Kitchen's 6th birthday
Anne Maine in honor of Jack Greeley - Tamarack Family Fun Day
Wes and Frances Manning in memory of Elsie Zevenbergen
William and Melissa Marsh in honor of Megan Morrill - Marsh Lemonade Stand
David and Anna Martin in memory of Eugene McFelea and in honor of the Carroll Grandchildren
Kathryn Martinez in honor of John Ben and Ava Shepperd
Sam and Patricia Mauro in honor of Jack Greeley - Tamarack Family Fun Day
Katherine and Tom May
John and Susie McCalla in honor of Kevin McCalla
Michelle McCarthy in honor of Alex Weaver - 10K Race
Leslie McGregor in honor of Jared McGregor
Rob and Ingrid Michael in honor of Jack Greeley - Tamarack Family Fun Day
Brian and Cherie McLaurin in honor of Laura McGinnis / Belk Fundraiser
Brian and Kristin Mehta in honor of Jack Greeley's 6th birthday
Jeffrey and Leslie Miller in honor of John Ben and Ava Shepperd
Syndee and Lawrence Miller in honor of Jack Greeley's 6th birthday
Robert and Cheryl Mitchell in honor of Grace Goldberger and Jack Greeley
Gregory and Natalie Morgan in honor of Laura McGinnis / Belk Fundraiser
Walter and Cheri Morris in honor of Jack Greeley
Beth Moses in honor of Alex Weaver - 10K Race
Daneill, Patricia and Brendan Mullen in honor of Jack Kitchens
Sayuri and Yoshiaki Nagao in honor of Jack Greeley's 6th birthday
Mark and Debra Nedervelt in honor of Alex Weaver - 10K Race
Howard and Sharon Nelson in honor of Jack Greeley - Tamarack Family Fun Day
Linda Holshouser Parks in honor of Laura McGinnis / Belk Fundraiser
Isabel Paul in honor of Alex Weaver - 10K Race
Jodi Pauly in honor of Jack Greeley - Tamarack Family Fun Day
Anthony Pedrone in honor of Jack Greeley's 6th birthday
Thomas and Margaret Petrick in honor of Jack Greeley's 6th birthday
Bryan and Laura Pett in honor of Jack Greeley's 6th birthday
Debra Ann Ponce De Leon in honor of Jack Greeley
Stanley Preston Jr. in honor of Alex Weaver - 10K Race
Matthew and Amy Quillen in honor of Alex Weaver - 10K Race
Christopher and Jan Rabin in honor of Jack Greeley
Duncan Reid in honor of Alex Weaver
Donna and Arnold Richard in memory of Sierra Woodward
Melissa Roberts in honor of John Ben and Ava Shepperd
Cindy Romanstine-Davis in honor of Laura McGinnis / Belk Fundraiser
Roger and Terry Romo in honor of John Ben and Ava Shepperd
Roxana Rosado in honor of John Ben and Ava Shepperd
Nancy Roseth in honor of Jack Greeley - Tamarack Family Fun Day
Loretta Ross in honor of Alex Weaver - 10K Race
Atlee Rutian Club in honor of Alex Weaver
Anne and Timothy Ryan in honor of Jack Greeley
Betty Sacra in honor of Alex Weaver - 10K Race
Joseph and Gail Saliba in honor of Jack Greeley - Tamarack Family Fun Day
Walter and Susan Sartor in honor of John Ben and Ava Shepperd
Carl and Terri Schleuder in honor of Steve Schleuder
Larry and Sharon Seay in honor of Laura McGinnis / Belk Fundraiser
John Schultz in honor of John Ben and Ava Shepperd
Amy Shapiro in honor of Jack Greeley - Tamarack Family Fun Day
Michael and Molly Shapiro in honor of Jack Greeley - Tamarack Family Fun Day
Kathleen and Gary Shaw in honor of Emily and Aimee Shaw
Lynda and Marc Shellist in honor of Jack Greeley
Aaron and Suzanne Siegel, MD in honor of Jack Greeley - Tamarack Family Fun Day
Steven and Kathleen Skwara in honor of Jack Greeley's 6th birthday
Eric and Lorna Smith in honor of Mitchell Smith
Elva Smith in honor of Mitchell Smith
W. Wallace and Yvonne Smith, Jr. in honor of Alex Weaver - 10K Race
June Snyder in honor of Alex Weaver - 10K Race
Julie and David Spokane in honor Jack Greeley
Amber and Rudy Stefanski in honor of Evan LeBeau's 2nd Birthday
Tami and Scott Stensby in honor of Jack Greeley - Tamarack Family Fun Day
Sandra Stenzel in honor of Pam Roesler's retirement and in honor of Kendall Julian
Gretchen Stieren in honor of John Ben and Ava Shepperd
Jennifer and James Sturgeon in honor of Jack Greeley - Tamarack Family Fun Day
James and Nancy Thomas in honor of Jack Greeley - Tamarack Family Fun Day
Wentong Tian in honor of Jack Greeley's 6th Birthday and Nicole Xia
Scott and Elizabeth Treiber in honor of Jack Greeley
Douglas and Pamela Troy in honor of Jack Greeley
Jeff Truskowski in honor of Jack Greeley's 6th Birthday
United Way of Greenville County Mitchell Rd. Elementary School In honor of Laura McGinnis
United Way of Orange County
United Way of the Piedmont, INC
Paul and Julie Von Werder Texas Hold Em raise in honor of Kenadee Reese
Julian
Iris Woodward in memory of Sierra Woodward
Rebecca and Derek Wagner in honor of Jack Greeley
Mark and Juli Walton in honor of Jack Greeley
Dawn and Robert Weiland in honor of Jack Greeley
Meg and Brian Wilson and family in memory of Jimmy Halloran on his birthday
Leslie Winton in honor of Jack Greeley - Tamarack Family Fun Day
Christopher Witty in honor of Mitchell Smith
Ellen Woodstein in honor of Jack Greeley - Tamarack Family Fun Day
Rock and Pam Woodward in honor of Tahnie Woodward and John Ben and Ava Shepperd
Kerry and Andrea Wortzel in honor of Alex Weaver - 10K Race
Lewis and Anne Wright in honor of Alex Weaver - 10K Race
Susan and James Wynne in honor of Jack Greeley - Tamarack Family Fun Day
John and Kelly Youngblood in honor of John Ben and Ava Shepperd
Vision and Mission Statement

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

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

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Mark Your Calendars for Upcoming Conferences!

**July, 2007**
The Cystinosis Research Network Family and Medical Conference in San Antonio, Texas. More information will be released soon at www.cystinosis.org

**August, 2010**
International Pediatric Nephrology Meeting in New York City. More information will be on www.cystinosis.org as the event gets closer

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