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Dr. Stephanie Cherqui at the 2009 CRN Family Conference

2009 Cystinosis Research Network Family Conference—A Great Success!

By Cheri Friend

The 2009 Cystinosis Research Network (CRN) Family Conference was held July 16-18 at Stone Mountain Park just outside Atlanta, Georgia. With over 300 family members, physicians, researchers and volunteers in attendance, this year's conference was our best ever! Included in these attendance numbers were 14 families who had never attended a family conference before. For those who have attended conferences in the past, you know how invaluable the family conferences are to building and strengthening professional and family relationships. These relationships are vital to us all as we navigate through the cystinosis journey!

The conference theme "Above & Beyond" was exhibited throughout the conference by our speakers, professionals and volunteers who all went the extra mile to ensure the conference experience was a positive one for all. Most notably, CRN recognized two very special individuals



with "Above & Beyond" Achievement Awards. We are proud to honor Dr. Bill Gahl and Dr. Jess Thoene for their extraordinary and on-going efforts to improve the lives of everyone in the cystinosis community. We are grateful to have these two unique individuals engaged in our mission.

For the 2009 conference, CRN engaged the services of a production company to provide us with photos and a professional video. The photos are available on the CRN website at www.cystinosis.org, click on Family Support, then Photo Gallery. The video can be viewed at http://www.youtube.com/watch?v=9tdUa_1mc5Y

Prior to the conference, the CRN Scientific Review Board met to review the currently submitted grant proposals.

The Cystinosis Research Network is committed to supporting and advocating research to achieve its vision of improved treatments and ultimately a cure for cystinosis. The CRN Executive Board reviewed the recommenda-

tions of the Scientific Review Board and made the decision to fund three additional grants. This brings CRN's current commitment for research grants in progress to over \$650,000.



Hunter Smith & Alex Greeley

Conference acknowledgements on page 18. More photos throughout newsletter!

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Vice President
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Paula Shal

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*denotes President Emeritus

Message from the President Christy Greeley

"Above and Beyond"

When I look back on the past year since publication of the last edition of *The Cystinosis Advocate*, I am amazed by the range of accomplishments in the cystinosis community. Most notably, the Fourth Cystinosis Research Network Family Conference was held July 16-18, 2009 at the Marriott Evergreen Conference Resort in Stone Mountain, Georgia. This year's theme was "Above and Beyond" and there is no doubt that we as a community did just that! Nearly 300 people from 25 states and 10 countries living with or involved in the care or research of cystinosis gathered to enjoy this unique opportunity to connect and share their experience and expertise. More than 60 families and 50 clinicians, researchers and professionals were in attendance during the three day conference.

One of the highlights of the conference was the recognition of Dr. Bill Gahl and Dr. Jess Thoene for their outstanding achievements and contributions to the cystinosis community. They received the first annual "Above and Beyond" award for their unparalleled dedication to both CRN and the cystinosis community. You can find a summary of the conference, as well as many photos from the event in this newsletter. CRN has also produced a video which is available on the website and which can be obtained for use at educational and fundraising events. It includes highlights from the conference which help illustrate CRN's vision and mission. We are proud of this new method which we can utilize to educate the public and medical communities about cystinosis.

CRN welcomes two new members to its Board of Directors: Tahníe Woodward and John Maccarone. Jen Wyman and Cheri Friend have taken on expanded responsibilities and accepted positions on the Executive Committee as VP of Development and VP of Family Support. You can find more information about each of these committed individuals in this newsletter. Please help us welcome them and thank them in advance for their service to our community.

You will also find updates from each of our standing committees, including:

Finance - CRN completed its annual audit which once again confirmed the fiscal health of the organization. The latest financial reports are provided for your information. The 2008 Donor Honor Roll is also included. We cannot thank our donors enough for their incredible generosity which allows us to provide so many services to the cystinosis community.

Development - Our fundraising efforts are expanding! Look for fundraising support materials, examples from past events, and information about utilizing the new CRN video and CRN display materials on the CRN website if you are interested in holding an event of your own. Inspiring stories of the many fundraisers which have been held this year in honor of so many incredible people who live with cystinosis are included, as well as a listing of future fundraisers.

Research - We are proud to report that, as a result of this year's Call for Proposals, three new grants will be funded by CRN. These studies represent an additional \$250,000 in research funding. The three new projects funded are:

"Feasibility of Cystinosin Replacement Therapy in Cystinosis", Dr. Jess Thoene, University of Michigan, Ann Arbor, MI



Christy, Jack, Alex, and Dave Greeley
Jack's Make-A-Wish, March 2009

"Quality of Life in Cystinosis Patients", Dr. Ewa Elenberg, Texas Children's Hospital, Houston, TX

"Proposal for a North American Cystinosis Research Platform", Dr. Paul Goodyer, Montreal Children's Hospital, Montreal, Canada, and Dr. Rick Kaskel, Children's Hospital at Montefiore, Bronx, NY

We welcome Dr. Elenberg, Dr. Kaskel, and Dr. Goodyer as new CRN funded investigators, and we look forward to our continued relationship with Dr. Thoene. We also wish to thank the CRN Scientific Review Board for their thoughtful review and recommendations regarding this years' submitted proposals.

This issue also features updates on other ongoing CRN funded studies, as well as updates from Raptor Pharmaceuticals on the progress of their development of the delayed release formulation of cysteamine.

Finally, we welcome Dr. Corrine Antignac and Dr. Roslyn Mannon as new additions to CRN's Medical Advisory Board. Their depth of expertise in cystinosis research and clinical experience will be a great asset to the MAB. We extend to them our deepest gratitude for their service.

Family Support - The main activity of the Family Support Committee this year has been the planning and execution of the 2009 Family Conference. We are also active in identifying and getting information and support to new families as they are diagnosed or as they enter into new phases of their journey. If you have not already, please go to the CRN website and click on the "Support Groups" link to join our Yahoo Email Support Groups which are a wonderful way to stay in touch with the rest of the community on a daily basis.

We are pleased to announce that the 2011 CRN Family Conference will be held in San Francisco, California and will be hosted by the Jordan Family. Look for specific dates and locations soon on the CRN Website and via email announcements. We look forward to meeting again in 2011 on the West Coast!

Education and Awareness - Updates on CRN's education and advocacy activities are included, as well as reports from other cystinosis organizations from around the world. CRN sent representatives to exhibit at the American Society of Pediatric Nephrology Meeting held in Baltimore, Maryland last May. CRN also attended the National Organization for Rare Disorders (NORD) Partners in Progress Summit and Member Organization meeting in May in Washington, D.C. Look for more information on both meetings within this newsletter.

One of the most exciting achievements of 2009 is the election of Marybeth Krummenacker, longtime CRN Board of Directors member and CRN co-founder, to NORD's national Board of Directors. This is a high honor and is in direct recognition of the years of dedication she has provided, not only to cystinosis, but also to the greater rare disease community as a whole. We congratulate her and look forward to her ability through this position to keep cystinosis on the national agenda and to keep our community more closely up to date on what's happening on the national stage in healthcare as it relates to rare disease.

Finally, we are proud to announce the recipient of CRN's educational scholarship award in this issue. Please join us in congratulating Shannon Keizer on her achievements.

As a final note, I'd like to recognize the extraordinary dedication of two individuals who have made this edition of *The Cystinosis Advocate* a reality. Paula Shal, CRN's Vice President for Education and Awareness is also our newsletter editor. As many of you know, she received a successful kidney transplant in October, right before our publication deadline. She worked on this newsletter practically up until she was admitted for surgery, sending me a half completed newsletter draft at 2am! Paula is an amazing individual who has never allowed her illness to interfere with the successful life she is leading. We are indebted to her for her unparalleled dedication to the CRN Board of Directors. And waiting in the wings as Paula took a well deserved break, Cheri Friend, CRN's Vice President of Family Support took over and completed the newsletter as her first attempt at editor! Cheri is another unbelievably hard working member of the CRN Board, always ready to lend a hand and pitch in to help the community, despite her full family life and her own personal challenges. I'd like to personally thank you both!

As always, CRN remains dedicated to finding improved treatments and an eventual cure for cystinosis while at the same time never losing sight of the importance of providing support to our community. Please consider becoming involved, whether it's as a committee volunteer, fundraiser host or board member, we need your help and you can make a difference.

Please feel free to contact me or any member of our Board of Directors with any questions or concerns you may have. Have a wonderful holiday season and may you be blessed with peace and good health in the coming year.

Warmest Regards,

Christy Greeley

President and Executive Director

CRN Welcomes New Board Members!

The CRN Board of Directors, by unanimous vote, would like to announce John Maccarone and Tahnie Woodward have been elected to the CRN Board of Directors.

The Board would like to recognize outgoing board member, Pam Woodward, for her many years of dedication to CRN. Pam served in many roles including VP-Family Support. Pam is best known for her ability to remember the names and the stories that go with members of the cystinosis communities.

Please take a moment to read the bios of our new board members below. We look forward to a busy and exciting 2010.



John, Arlene, Brandon & Johnny Maccarone

John Maccarone

John Maccarone was born and raised in Glen Cove New York. After high school he attended SUNY Delhi where he received his degree in Plumbing and Mechanical Design. John also received a degree in Plumbing and Sprinkler Theory and Design from the Mechanics Institute in New York City. He presently owns and operates Maccarone Plumbing Inc. which employs over 90 people. John now resides in Laurel Hollow, New York with his wife, Arlene and their two sons Brandon, who is 9 years old and Johnny, who is 6 years old. Both of John's sons were diagnosed with Cystinosis, Brandon was seven years old just about to turn eight and Johnny was five years old. Both Brandon and Johnny are required to take eye drops several times throughout the day for their Cystinosis and seem to be responding very well to the drops. Brandon and Johnny are both being treated in New York by Dr. Frederick Kaskel at Montefiore and by Dr. Gahl of the National Institutes of Health.



Kacy Wyman and Tahnie Woodward

Tahnine Woodward

Tahnine was diagnosed with Cystinosis at 16 months. She had her kidney transplant at age 11 with her mother being the donor. Tahnine celebrated the 15 year anniversary of her transplant in October, 2009. She feels lucky to celebrate such a successful milestone. Tahnine graduated from the University of Utah in May of 2008 with her Bachelor of Science degree in Human Development and Family Studies with a Child Life emphasis. She is dedicated to having a career as a Child Life Specialist and will complete an in hospital internship in the near future. She is beyond thrilled to be a new member of the board and looks forward to contributing her knowledge of coping with Cystinosis for 25 years as well as her extensive education in Child Life, in hopes of giving back to the community that has given her so much. She lives in American Fork, Utah, with the love of her life, Rory, and their miniature dachshund, Jack.

CRN Attends NORD Partners in Progress Rare Disease Summit



Jean Campbell of NORD

On May 14, 2009, representatives from the Cystinosis Research Network's Board of Directors,

including Christy Greeley, President and Executive Director, Jose Morales, President Emeritus, and Marybeth Krummenacker, Director, attended the NORD (National Organization for Rare Disorders) annual Member Organization Meeting, Partners in Progress Rare Disease Summit and Gala in Washington, D.C.

The Rare Disease Summit included a true Blue Ribbon Commission of some of the most influential thinkers and policy makers in health-

care, including David Kessler, former Commissioner of the U.S. Food and Drug Administration, Timothy Cote, Director, Office of Orphan Product Development, U.S. FDA, Stephen Groft, Director, Office of Rare Disease Research, NIH, Tommy Thompson, Former Health and Human Services Secretary and four-term Governor of Wisconsin, Janet Woodcock, Director, Center for Drug Evaluation and Research, U.S. FDA and Francis Collins, Former Director, National Human Genome Research Institute, NIH.

CRN was one of a select number of patient advocacy representatives that were able to add their perspective, along with government and industry representatives, to this discussion meant to set a policy agenda for NORD to move forward with to help create a more

responsive environment for patients with rare diseases.

CRN feels that our advocacy efforts on behalf of the community are just as vital as the funds we spend on research and the family support services we provide. We are proud of our affiliation as a Member Organization of NORD, and we are convinced that banding together as a rare disease community will not only speed improvements in treatment, but will also help to solve the many other problems that go hand in hand with medical issues, including insurance coverage and reimbursement and disability qualifications. As Peter Saltonstall, President and CEO of NORD stated, "At this critical juncture in our nation's health care history, our advocacy and leadership are more important than ever before."

CRN's Marybeth Krummenacker to Serve on NORD's National Board of Directors

Six individuals with expertise in areas related to rare disease awareness and advocacy have been elected to the Board of Directors of the National Organization for Rare Disorders (NORD). NORD represents the nearly one in 10 Americans with rare diseases (www.rarediseases.org).

"We are thrilled that these individuals have accepted the call to help guide NORD through this important period in its history," said NORD President and CEO Peter L. Saltonstall. "NORD is poised for growth at this time. The patients and families we serve need strong leadership at the national level. And the role of our Board of Directors is critically important. We are grateful to these individuals for sharing their expertise."

Marybeth Krummenacker is the immediate Past VP of Education and Awareness for the Cystinosis Research Network, and has held numerous positions over the years in that nonprofit organization. Ms. Krummenacker's daughter was diagnosed with cystinosis more than 20 years ago, and since then Ms. Krummenacker has been active on the national level in education and advocacy efforts. She is particularly interested in activities to educate families on topics related to living with rare diseases and to increase understanding of rare diseases among medical professionals.

We as a community are proud of the recognition that Marybeth's election to NORD's Board of Directors provides and we think that it is an ideal opportunity for cystinosis to have a

voice through her in the national rare disease discussion, particularly with regard to public policy decision making.



Marybeth Krummenacker

CRN Education and Awareness Update

By Paula Shal
Vice-President, Education and Awareness

As I have struggled with my own complications due to cystinosis over the past year, it reminds me of what I love about Cystinosis Research Network. We are more than a community. We are a family. We check in on each other, and we help each other out.

I was disappointed that I was unable to attend the 2009 CRN Family Conference. I was looking forward to seeing all the families and introducing some of our phenomenal speakers.

I would like to take a moment to thank Marybeth Krummenacker (former VP-Education and Awareness) for stepping into my role at

the conference as well as at the CRN Board Meeting. Marybeth's presence and stories are always inspiring to our community.

I would also like to thank Cheri Friend for her work on the newsletter as I tend to my health. I think everyone who knows Cheri would agree it is a pleasure to have her back on the CRN board!

Dan Julian and Mack Maxwell have been integral in stepping up to help with the CRN website. They have done a fantastic job adding timely updates so that our site is as informative and current as possible. Thank you, Mack and Dan!

As always, Christy Greeley has been the glue holding our board together when times are challenging. For that, I am so grateful.

As we look ahead to 2010, CRN will continue to forge ahead in educating others about cystinosis. The ASPN annual meeting will be held in Vancouver, Canada May 1-4, and CRN will give strong consideration to sending representatives.

We still plan to publish a newsletter two times a year.

We are always looking for new families to feature in the newsletter, so please contact me at pshal@cystinosis.org if you are interested.



Shannon Keizer
Scholarship recipient

CRN Participates in the Pediatric Academic Societies' Annual Meeting



Elva Smith

Elva Smith and Karen Gledhill represented CRN at the Pediatric Academic Societies' Annual Meeting in Baltimore, Maryland on May 1-3, 2009. This meeting offered a unique opportunity to educate the pediatric medical community about cystinosis and promote CRN's mission and vision.

CRN was able to interact and share information with the various children's hospitals who were also represented at the meeting. Elva and Karen were able to speak with the many physicians in attendance and educate them about cystinosis. Participation in these types of meetings is integral in our mission to educate the medical community about cystinosis.



Karen Gledhill

CRN Financial Update

For the fiscal year 2008, CRN received \$412,000 in total income and \$406,000 in total expenses giving an overall net income of \$6,000 for the year. More than 70% of the total expenses went toward research. Also, as a requirement of the state of Illinois, CRN had both 2007 and 2008 external audits completed and the auditor verified our financial statements to be fairly presented and conforming to GAAP (Generally Accepted Accounting Practices).

For the current fiscal year January through September 2009, CRN has received \$290,000 in income and incurred expenses totalling \$292,000. Research grants paid to date are \$128,000 or 44%. The CRN family conference makes up \$85,000 or 29% of total expenditures. Overall CRN anticipates that 2009 will meet budget expectations.

My fellow board members and I have worked diligently to bring CRN to the next level of transparency and accountability from a financial perspective. With the successful completion of annual audits, correctly classifying all transactions in updated financial software, and complete compliance to GAAP standards, CRN's priority is to maintain its integrity in the non-profit world. We are looking forward to the end of another successful year and the beginning of 2010.

Financially Yours,
Brittney LeBeau-CRN Treasurer



Mack Maxwell & Lynne Blissit



Paul Goodyer & Francesco Emma



Morgan Friend, Heidi Hughes & Andrew Hoffman



The Kitchens Family

CRN—2008 Profit & Loss Statement

Jan - Dec 08

Ordinary Income/Expense

Income

41000 · Donations

43400 · Direct Public Support 95,283.55

44800 · Indirect Public Support

44820 · United Way, CFC Contributions 26,832.78

44830 · Missionfish 140.85

44840 · CafePress 128.00

44850 · Causes on Facebook 214.36

44860 · Goodsearch 149.63

44870 · Network for Good 640.00

Total 44800 · Indirect Public Support 28,105.62

Total 41000 · Donations 123,389.17

43440 · Gifts in Kind—Goods 18,214.00

44700 · Fundraising 208,559.74

44700 · Grants 52,000.00

45000 · Investments 9,364.61

46400 · Other Types of Income

46430 · Miscellaneous Revenue 14.74

46400 · Other Types of Income—Other 18.58

Total 46400 · Other Types of Income 33.32

Total Income 411,560.84

Expense

65000 · Operations

60920 · Business Registration Fees 275.00

61120 · Insurance 2,205.58

61230 · Miscellaneous 715.49

62110 · Accounting Fees 5,820.00

62120 · Bank Charges 5.00

62150 · Outside Contract Services 1,541.94

62200 · Grant Payments 285,154.60

62890 · Rental of Facilities 23,884.03

63100 · Scholarships 1,000.00

64000 · In-Kind Expenses 18,214.00

65010 · Books, Subscriptions, Reference 2,375.25

65020 · Postage, Mailing Service 6,048.76

65030 · Printing and Copying 5,500.00

65040 · Supplies 15,598.51

65050 · Telephone, Telecommunications 22,610.85

65060 · Credit Card Processing Fees 77.50

65070 · Bank Fees 830.00

68300 · Travel and Meetings

68200 · Exhibit Costs 1,143.11

68305 · Registration 2,345.57

68320 · Airfare 4,381.70

68330 · Meals and Food 261.81

68340 · Hotel 5,014.81

68350 · Transportation 624.60

Total 68300 · Travel and Meetings 13,771.60

Total 65000 · Operations 405,628.11

Total Expense 405,628.11

Net Ordinary Income 5,932.73

Net Income 5,932.73



**Christy Greeley &
Dr. William Gahl**

CRN –2009 Profit & Loss Statement

Jan - Sept 09

Ordinary Income/Expense

Income

41000 · Donations

43400 · Direct Public Support 253,728.36

44800 · Indirect Public Support

44820 · United Way, CFC Contributions 17,223.80

44830 · Missionfish 8.00

44870 · Network for Good 142.89

Total 44800 · Indirect Public Support 17,374.69

Total 41000 · Donations 271,103.05

44700 · Grants 15,000.00

45000 · Investments 3,483.57

Total Income 289,586.62

Expense

65000 · Operations

60920 · Business Registration Fees 180.00

61120 · Insurance 2,686.42

62110 · Accounting Fees 5,100.00

62120 · Bank Charges 57.44

62150 · Outside Contract Services 1,176.00

62200 · Grant Payments 128,099.60

62840 · Equip Rental and Maintenance 4,500.00

62890 · Rental of Facilities 112,532.27

65010 · Books, Subscriptions, Reference 300.00

65020 · Postage, Mailing Service 1,035.48

65030 · Printing and Copying 8,107.56

65040 · Supplies 6,517.12

65050 · Telephone, Telecommunications 6,391.25

65060 · Credit Card Processing Fees 735.91

68300 · Travel and Meetings

68200 · Exhibit Costs 2,699.78

68305 · Registration 300.00

68320 · Airfare 6,975.24

68330 · Meals and Food 53.14

68340 · Hotel 2,370.19

68350 · Transportation 535.36

68300 · Travel and Meetings - Other 1,314.32

Total 68300 · Travel and Meetings 14,248.03

Total 65000 · Operations 291,667.08

Total Expense 291,667.08

Net Ordinary Income –2,080.46

Net Income –2,080.46

CRN Research Update

By Elva Smith—Vice President, Research

CRN is pleased to inform you that we have added two new members to our Medical Advisory Committee, Dr. Roslyn Mannon of the University of Alabama at Birmingham, and Dr.

Corinne Antignac, MD, PhD of Necker Hospital, Paris, France. CRN extends a sincere thank you to these doctors for their willingness to be a part of the Cystinosis Research Network. We are confident that their presence on, and contributions to, our Medical Advisory Committee will be a most positive addition. We look forward to working with them and our other MAC members to improve the quality of life and enhanced outlook of all of those affected by cystinosis.



Dr. Trauner at the 2009 Family Conference

Recently completed Grant Studies:

Donald Cairns, PhD School of Pharmacy, The Robert Gordon Univ., Aberdeen, Scotland, has completed his study "Design and Synthesis of Novel Prodrugs for the Treatment of Cystinosis". Grant awarded: 31 Aug. 2005 for 3 years: October 2005 - September 2008. Total award: \$97,928.00. Dr. Cairns' final report can be found on the cystinosis.org website.

Donald Cairns, PhD School of Pharmacy, The Robert Gordon Univ., Aberdeen, Scotland, with Dr. Rachel Knott, and Dr. Graeme Kay, "Evaluation of Novel Prodrugs for the Treatment of Nephropathic Cystinosis", Grant awarded: 1 October 2007 1 year Fall 2007 - Fall 2008. Total award: Pounds 35,000.00 (approximately US\$70,000.00)

The final report on this study was received on September 3, 2009 and can also be found on the cystinosis.org website.

Elena Levtchenko, MD, PhD Univ. Medical Center Nijmegen, The Netherlands, has submitted a report on her grant entitled "Study of ATP metabolism in human cystinotic proximal tubular cells and in humans with cystinosis in vivo". The grant was awarded: 11 September 2006 for 1 year, Jan. 2007 thru Dec. 2007. Total award: \$68,090.00.

However, Dr. Levtchenko's email accompanying the "final" report states that the "In vivo" part of this project is not finished yet due to the technical difficulties with the MRS apparatus, but we have good hope that the problem will be solved

and this part of the study will be finished in 2009". This report can be found on the cystinosis.org website.

Doris Trauner, MD Dr. Trauner was awarded a travel grant entitled "Visual Spatial and Visual Motor Skills in Cystinosis: Longitudinal Study", a one-time travel grant of \$3,000.00 plus accommodations for expenses for 4 research personnel to travel to Atlanta to test children during the CRN family conference this past July. This project was a great success as Dr. Trauner reported that the testers obtained lots of data - "we tested 27 children and adults! I think that's a record for 4 days!" The tests are currently being scored and checked, and result letters will be sent to the parents. The next step will be analysis of the data. Dr. Trauner further commented: "This was a very successful meeting for our research. Thank you again for your support!"

Grant studies still in progress:

Jess Thoene, MD, University of Michigan, Ann Arbor, "Tissue Repository for Cystinosis", start date: 21 Nov. 2006 - ongoing; Total award: \$26,206.00; Balance remaining on grant: \$6,551.00.

Catherine Tuleu, PhD, Univ. of London, School of Pharmacy, and Ken Nischal, Olufemi Rabi, Rajnish Sekhri, Wm Van't Hoff and Bola Lawal: "Development of cysteamine in situ gelling system for the topical treatment of corneal crystals in cystinosis", Agreement signed 24 Oct. 2006; Grant awarded January 2007 for 3 years, 1 Mar 2007 - Feb. 2010. Total award: 103,000.00 pounds, approximately \$164,078; Balance remaining on grant: 67,400 pounds, approximately \$107,368.

Viki Kalatzis, PhD, Eric J. Kremer, PhD, Institut Genetique Moleculaire de Montpellier, France, "Gene transfer studies for cystinosis" Grant awarded 29 Aug 2007, 2 yrs. Fall 2007 - Fall 2009. Total award: Euros 75,900.00, approximately US\$104,619.48. The 6 and 12 month progress reports on this study were noted in the fall 2008 Newsletter. An 18 month progress report was received 17 June 2009 and can be found on the cystinosis.org website. Final payment on this grant was made on 20 June 2009; however, the final report is still pending.



Dr. Elena Levtchenko

Cystinosis Research Update (cont.)

The three grants that were awarded as a result of the 2008 Call for Proposals are still in progress and include:

Leticia Belmont, M.D., Unidad de Genetica de la Nutrician, Instituto Nacional de Pediatria, Mexico. "Determination of Intra-leucocitary Cystine by High Performance Liquid Chromatography (HPLC) in Patients with Cystinosis". Grant Awarded: 5 November 2008 Total award: \$31,972.00; Balance remaining on grant: \$15,986.00

Henk J. Blom, M.D., M.M.C. Wamelink, and E. Levtchenko, VU University Medical Center, Amsterdam, The Netherlands: "Newborn Screening of Cystinosis". Grant Awarded: 5 November 2008; Total Award: 45,000 euros (approximately \$67,500.00); Balance remaining on grant: 33,750 euros.

Francisco Emma, M.D. and Anna Taranta, Ph.D., Bambino Gesù Children's Hospital and Research Institute, Rome, Italy: "Functional Characterization of Cystinosis-LKG".

Grant Awarded: 5 November 2008; Total Award: \$114,480.00. The first progress report on this study was received on 28 August, 2009 and can be found on the cystinosis.org Website. The balance remaining on this grant is \$85,860.00.

New Grant Studies Funded in 2009:

"Feasibility of Cystinosis Replacement Therapy in Cystinosis", Dr. Jess Thoene, University of Michigan, Ann Arbor, MI. Grant awarded 25 September 2009 for a total of \$165,732.00. The initial payment of \$27,622.00 was made on 02 October 2009. Balance remaining on grant: \$138,110.00.

"Quality of Life in Cystinosis Patients", Dr. Ewa Elenberg, Texas Children's Hospital, Houston, TX. Grant awarded 25 September 2009 for a total of \$21,000.00.

"Proposal for a North American Cystinosis Research Platform", Dr. Paul Goodyer, Montreal Children's Hospital, Montreal, Canada, and Dr. Rick Kaskel, Children's Hospital at Montefiore, Bronx, NY. Total award: \$36,000.00.

CRN's current commitment for research grants still in progress, including those awarded as a result of our 2009 Call for Proposals, totals over \$650,000.00. We at CRN are appreciative of all our researcher's dedication and hard work in our quest for improved treatment and eventually a cure for cystinosis. We extend a sincere thank you to all of them and look forward to our continued positive cooperation and progress.



Dr. Belmont, Christy Greeley & Cynthia Fernandez



Steven Schleuder, Christian Sproedt, Pam Woodward, Terri Schleuder & Tahnine Woodward



Jan & Kenadee Julian, Kacy, Tim & Jen Wyman



Brad Thurman, Francois Cuppey, Gretchen Thurman & Lorna Smith

Participate in Cystinosis Research

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

Stress and Coping in Cystinosis

The UCSD Pediatric Neurology Research Group is conducting a study to examine stress reactions, coping responses, quality of life, and medical adherence in individuals with cystinosis. Participants will include individuals with cystinosis ages 12 years through adulthood. This study will involve approximately two 2-hour cognitive-behavioral testing and questionnaire sessions. The testing and questionnaires will help us learn more about stress, coping, quality of life, and adherence in cystinosis.

Participation in this research study is completely voluntary. Participants will be paid \$25 for each session. If you would like to participate in the Stress and Coping study or if you would like more information, please contact Amy Spilkin Ph.D. at UCSD: aspilkin@ucsd.edu or 858-822-6800.



The Haynes family

Raptor Pharmaceutical Corp. Advances DR Cysteamine in Clinical Trials

Raptor's DR Cysteamine [link to: http://www.raptorpharma.com/dr_cysteamine_cystinosis.html], an investigational, delayed-release (DR) oral formulation of cysteamine bitartrate, is being studied for the potential treatment of nephropathic cystinosis. Our DR formulation may require less frequent dosing and reduce gastrointestinal side effects.

So far 7 patients have completed the pilot study, and we are learning quite a bit about the dosing and administration of the delayed release product relative to Cystagon®. Before finalizing the dose and administration portions of the protocol for the planned phase 3 trial, we will enroll up to 3 additional patients in an amended pilot protocol. We plan to enroll them in early fall, 2009.

Raptor extends its thanks to all who have participated in the studies that have brought us to this point and appreciates the effort made by both patients and families for all study participation.

In addition to completing the pilot study, we have been working hard to get the phase 3 study moving forward. We expect to begin recruiting patients this year. We are making revisions to the phase 3 protocol in order to minimize days in the clinic and reduce the travel burden on patients and families. The current phase 3 protocol calls for:

- 1 Screening Visit
- 7 night/8 day hospital visit
- 2 weeks (minimum) of home use of the new drug
- 3 night/4 day additional hospital visit

Patients eligible for the phase 3 study must be on a stable dose of Cystagon® for 21 days prior to starting the study, be able to swallow the capsules whole, not have received a kidney transplant and take all medications orally, not through a gastric tube. The current plan is to enroll approximately 20 patients.

An extension study to determine the safety of long-term administration of Cysteamine Bitartrate Delayed-Release Capsules is also planned. Patients who complete the phase 3 study will be offered the opportunity to be treated with Cysteamine Bitartrate Delayed-Release Capsules until the product is approved by FDA or until Raptor terminates RP103 development for this indication for any reason. Details will be forthcoming once phase 3 planning is complete.

Please contact your doctor or check out www.clinicaltrials.gov [link to: <http://www.clinicaltrials.gov/ct2/results?term=raptor+cystinosis>] for further information.

Raptor may be reached by email: clinicaltrials@raptorpharma.com or phone: 1-888-270-3828.



Dr. Rioux—Medical Director at Raptor Pharmaceuticals



Ted Daley of Raptor & Mick Swift of CF Ireland

Participate in Cystinosis Research



Cystinosis Research Network, Inc.

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To patients and parents of children with cystinosis:

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

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

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

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

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



Upcoming Family and Medical Events

May 1-4, 2010

ASPEN Annual Meeting
Vancouver, Canada

July 16-18, 2010

2010 Genetic Alliance
Annual Conference
Bethesda, MD

Aug. 29-Sept. 2, 2010

Fifteenth Congress
of the IPNA
New York, NY

Nov. 16-21, 2010

ASN Renal Week
Colorado Convention
Center
Denver, CO

July, 2011

2011 CRN Family
Conference
San Francisco, CA

CRN Sponsors Cystinosis Symposium at Congress of the International Pediatric Nephrology Association (IPNA)

August 29 – September 2, 2010

The planning of the Congress of the International Pediatric Nephrology Association (IPNA) meeting continues to move forward as we are now less than one year away. Dr. Rick Kaskel, who is the Congress President has been the driving force behind our involvement in this very important meeting. He and Dr. Bill Gahl are working together to formulate the agenda and the speakers for the symposia on cystinosis that will take place at this meeting. This is a tremendous opportunity for the cystinosis community and the committee of Jose Morales, Marybeth Krummenacker and Christy Greeley have had meetings and conference calls regarding our role in this all important meeting. The Congress of almost 1500 members representing 89 countries, is expected to draw the largest crowd of pediatric nephrologists ever from around the world to this premier location....New York City. Cystinosis Research Network has committed to funding a portion of the symposium that will be dedicated to cystinosis, with extraordinary speakers who will be addressing the issues of today. Below is a copy of the tentative agenda:

IPNA Symposium on Cystinosis New York City Tuesday, August 31, 2010

| | | |
|-----------|--|--|
| 1:00-1:30 | Plenary: Cystinosis Introduction | W. Gahl, Bethesda, MD |
| 1:30-2:30 | Platform Talks | Chairs: J. Schneider, UCSD/R. Kleta, London |
| | Growth Hormone in Cystinosis | Elke Wuhl, Heidelberg |
| | Cell Death in Cystinosis | Elena Levtchenko, Leuven |
| | Electrophysiological Properties of CTNS | Brune Gasnier, Paris |
| | Newborn Screening for Cystinosis | S. Hahn, Seattle/T.Vilboux, Bethesda |
| 2:30-3:00 | Panel Discussion: Availability of Cysteamine and Leucocyte Cystine Assays in Less Well Developed Countries | Chair: W. van't Hoff, London |
| | Vera Koch (or H. Vaisbach) - Sao Paulo, Brazil | |
| | Neveen Soliman — Cairo, Egypt | |
| | Rezan Topaloglu— Ankara, Turkey | |
| | Leticia Belmont—Mexico City | |
| | Orphan Europe Rep.— Paris | |
| 3:00-3:30 | Break | |
| 3:30-4:00 | Controversies | Chair: C. Langman, Chicago, IL |
| | Indomethacin for Polyuria in Cystinosis | P. Goodyer, Canada |
| | Dosing of Cysteamine in Children and Adults; | |
| | Treatment of Newborns and Pregnant Women | J. Thoene, Ann Arbor, MI |
| 4:00-4:30 | Short talks | Chairs: G. Nesterova, Bethesda/F. Emma, Rome |
| | (Five 3-min talks + 2 min questions by junior investigators) | |
| 4:30-5:00 | Plenary: Mouse Models for Studying Cystinosis | C. Antignac, Paris |
| 5:00-6:00 | Poster Session-CRN-sponsored Research | |

Cystinosis Foundation Ireland Update

At Cystinosis Foundation Ireland we are delighted to provide an update for the CRN Newsletter. Our Chairman Mick Swift attended the CRN Conference in Atlanta this summer which provided a great opportunity to catch up with all of our friends and also to work with CRN to see how we can all work more effectively together.

Supporting research continues to be our main aim, the challenge to continue to raise funds is growing for all of us. Nevertheless we are fortunate to have a small and very motivated team of supporters who are constantly thinking up of new ideas to help us raise money to support our research projects.

Among the fund raising events we have been involved with in 2009



Christy Greeley, Marc Tewey,
Mick Swift & Jose Morales

- We had two lady Marathon runners who took part in the Dublin City Marathon who were also joined by a gentleman, who disguised himself as Donald Duck!
- An annual cross country race wearing fancy dress and Wellington boots takes place in a tiny village in Co. Kilkenny each New Year's Day. We were lucky enough to be awarded €500 from the proceeds of this race in January.
- A fun night out was held at Easter in Dublin at a greyhound race track.
- Our sixth annual Golf Classic was held in May where 22 teams took part in a competition on one of our rare warm and sunny days! We held a dinner that night where Dr. Patrick Harrison, one of our researchers from University College Cork used several golfing analogies to explain his work very clearly. A raffle and auction topped off the evening.
- 40,000 women (and some men dressed as women!) take part in the Womens' Mini Marathon each June Bank Holiday Monday in Dublin. This year about 30 of those participants were doing so on our behalf.
- 4th July was a big day on our fundraising calendar: Two of our friends, Ann and Shannon swam 2.2km across Galway Bay on a very typical Irish day – grey, wet and windy. They survived and were thrilled with their personal achievement. Just outside London, England, on the same day seven weary men were completing a 100 mile walk which began on 2nd July up in Birmingham. They arrived to a heroes' welcome, a hog roast and a summer fete on the village green where they rested their blisters and aching legs.
- In August we found four new supporters who were impressed by the effort Ann and Shannon made in Galway and decided to dedicate the proceeds of their fun run around the Streets of Galway to Cystinosis research.

Coming up in October we are holding a "Mamma Mia" Ladies Night which promises to be lots of fun, although some men have been put out that they cannot attend!

In terms of research we are currently funding four research projects, Don Cairns team at Robert Gordon University in Aberdeen, Dr Minnie Sarwal's work in Stamford, Dr Patrick Harrison at University College Cork in Ireland and also Dr Philip Newsholm at University College Dublin.

As an Irish Charity we have been successful in securing joint funding from the Irish government through the Health Research Board for Dr Sarwal and Dr Harrison's work. We are indebted to all the international peer reviewers who have helped us in our work to date. We have just learned in the past few weeks that a new project with Dr Philip Newsholm has been successful in securing joint funding from the Irish Health Research Board.

Kind regards,

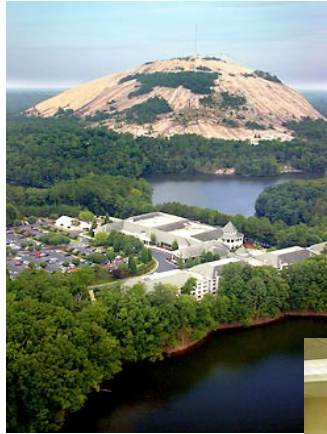
Mick Swift



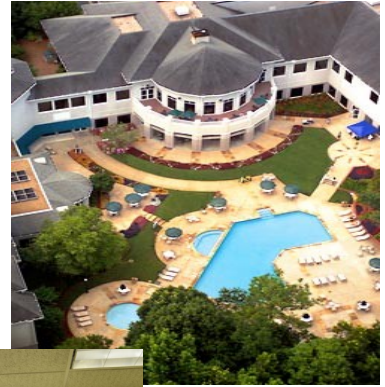


Every picture tells a story...

The 2009 CRN Family Conference



Scenic Stone Mountain Park — location of the 2009 CRN Family Conference



The Marriott Evergreen Conference Resort



The registration staff takes a break for a photo opportunity

“Excellent conference, I learned a lot that I plan on speaking with my doctor about. I know so much more about cystinosis than I did when I came!”

“Meeting other families who are going through this journey with us has been invaluable.”



Families enjoying the CRN reception on Thursday evening





Our group of distinguished speakers share their knowledge and insights on cystinosis



During the conference, the children enjoyed the many activities provided by the daycare and got a chance to meet new friends





Cheri Friend, Lorna Smith, Elva Smith
2009 CRN Conference Host Families



Dr. Thoene & Dr. Gahl receiving
"Above & Beyond" Awards from
CRN President Christy Greeley

CRN would like to express our gratitude to the following individuals and organizations that went "Above & Beyond" and made financial contributions towards the 2009 CRN Family Conference:

Sigma Tau

Cystinosis Research Foundation

C.H. Robinson Worldwide, Inc.

Raptor Pharmaceuticals

Kakkis Everylife Foundation

Cystinosis Foundation – Ireland/Mick Swift

Bryant Family

Croce Family

Ellerbrock Family

Flerchinger Family

Greeley Family

Jordan Family

Kazian Family

Langley Family

Maxwell Family

McGinnis Family

Melang Family

Robert Moore

Roxanne Munch

Pineros Family

Elva Smith

Wyman Family

Yearwood Family

CRN is pleased to announce that the 2011 Family Conference will be held in the San Francisco, California area and will be hosted by the Jordan family.

Start planning and saving now so you can join us in 2011!



The Jordan Family

Development Update

By Jen Wyman, Vice President, Development

Snowflakes melt alone - but together they can be traffic stoppers!

Teamwork allows common people to attain uncommon results.

Some people want it to happen, some wish it to happen, others make it happen.

Volunteers aren't paid, not because they are worthless, but because they are priceless.
Anonymous

Two things changed my life...Kacy's diagnosis with Cystinosis and the Cystinosis Research Network or CRN. One brought me desperation...the other brought me hope.

CRN is a life line that provides its members with constant support via the website, newsletters, e-groups and conferences. Our loved ones thrive as well as they do because this organization exists. The endless hours of volunteer work from it's members and the countless hours of research from our scientific board make the lives of those affected by Cystinosis richer and more fulfilling. Without it we would feel alone and uncertain. We would lack guidance and knowledge and support. We would lack hope and without hope we have nothing.



Brittney LeBeau, Christy Greeley & Jen Wyman

Unfortunately, volunteer organizations cannot survive on hope alone. Financially they depend on private donations, fundraising events, sponsorship, and grants. The amazing research that is funded and the family/medical conferences that are offered have to be paid for.

We must GIVE in order to RECEIVE.

To those of you who have helped financially through private donations, attending and/or hosting events, thank you. We hope you will continue to do so. To those of you who have not I ask you, BEG you, to consider it. The thought of putting together a fundraising event can seem daunting and overwhelming. But it doesn't have to be. My suggestion to you is to start small, let it grow and build. You will be amazed by the community support that comes your way and the warmth that giving back brings to your heart.

Please visit the website, check out the new "virtual fundraising packet" for ideas and suggestions on holding your own event. And as always, feel free to email me directly with questions at jenniwyman@att.net.

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.
Margaret Mead



Make an Online Donation Through PayPal

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

- You can dedicate a donation to someone specific. PayPal passes along your dedication to CRN.
- You will receive a record of your contribution for tax purposes.
- Go to www.cystinosis.org and click on the "Donate" link to begin!

2009 Fundraising Calendar

| Date | Event | Location | In Honor Of |
|--------------|---|--|----------------------|
| January 16 | 3rs Annual "Shoot for the Cure" Pancake Supper | Whitesboro High School, Whitesboro, TX | Mason Reed |
| February 3 | Stash for Cash | Bloomfield Hills, MI | Kacy Wyman |
| February 28 | Miracles at Milleridge | Jericho, NY | Laura Krummenacker |
| March | Ricardo, Inc. Jeans for a Cause | All U.S. Ricardo, Inc. Offices | Steve Schleuder |
| March | Jack Greeley Birthday Letter Campaign | N/A | Jack Greeley |
| March 7 | 3rd Annual Cause-2-Bowl | Bloomfield Hills, MI | Kacy Wyman |
| March 21 | Kenadee Julian's Benefit for CRN | Sherman, IL | Kenadee Julian |
| April 4 | Spaghetti Dinner and Silent Auction | Peru, IL | Jakob Ellerbrock |
| May 3 | 5K Fun Run/Walk | Bloomfield Hills, MI | Kacy Wyman |
| May 21 | Kinner & Co. Dance Spring Performance | Sherman, IL | Kenadee Julian |
| June 13 | C.H. Robinson Golf Tournament | Lehi, UT | Tahnie Woodward |
| June 19 | Summer Beach Party | Bloomfield Hills, MI | Kacy Wyman |
| July 26 | Bowling for a Cure | Independence, OH | Victor Gardner |
| August 1 | Special Kids Network Golf Tourney | Long Grove, IL | Jack Greeley |
| September 21 | Plumbing Contractors of Long Island Golf Outing | Bay Shore, NY | The Maccarone Family |
| October 18 | Family Fun Day | Lincolnshire, IL | Jack Greeley |
| November 1 | Wyman Holiday Letter Campaign | N/A | Kacy Wyman |
| November 6 | Senior Tennis Mixer | Dearborn, MI | Kacy Wyman |

Whitesboro Bearcat Basketball host 3rd Annual Shoot for the Cure Night



The Reed Family at the 2009 CRN Family Conference

On January 16, 2009 the Whitesboro Basketball Program hosted its' 3rd Annual Shoot for the Cure Night in honor of Mason Reed. Mason and his family were in attendance and the community response was awesome. A pancake dinner was held and \$1500 was raised. Mason was also an honorary member of the basketball team that night and introduced in front of a standing crowd. The boys basketball team also presented Mason with an autographed jersey. "Our boys in this program are outstanding. They are unselfish kids always willing to help out. They realize the impact they have as role models and leaders. We have a supportive community as well." (Shad Reed, Head Boys Basketball Coach and Mason's Uncle) KXII news also did an

extensive story on the evening and conducted several interviews. "I wanted our viewing area to get an idea of the type of disease we're dealing with. Most people have no clue what Cystinosis is. It was a great opportunity to present some information to the viewing area and tell people about Cystinosis." (Shad Reed) The evening wouldn't have been a success without the help of some special people. Many local businesses and parents contributed to the cause and the Bearcat Basketball Program would like to thank all involved.



Illinois Community Rallies Around the Ellerbrock Family



Jakob Ellerbrock

The Ellerbrock family hosted a fundraiser in honor of their son, Jakob Ellerbrock on April 4, 2009. It included a spaghetti dinner and featured Dewey Oxburger—one of the hottest local bands. The fundraiser was a huge success, raising \$5000 for CRN as well as tons of awareness for cystinosis.

had just not heard about the fundraiser. In all, their Tupperware party raised \$700! The Ellerbrocks can testify that the party was a simple way to raise money for a great cause.

The Ellerbrocks would like to thank everybody who participated in their events. For a small town, the results were above and beyond anything ever expected from family and friends.



Jakob Ellerbrock surrounded by Tupperware

When so many items were coming in for the silent auction, one particular lady who donated a basket of Tupperware came up with the idea of having a Tupperware fundraiser. The Ellerbrocks thought, "Everyone likes Tupperware," so they hosted a Tupperware party in which 40% of the purchases would go directly



Mary and J.J. Ellerbrock

The Long Island Plumbing Contractors Association Raises \$50,000 for CRN at Annual Golf Outing

By: John Maccarone and Marybeth Kruppenacker



The Long Island Plumbing Contractors Association has held a charity golf outing for the last 14 years. This year was particularly special as the Cystinosis Research Network was the charity chosen to receive the proceeds from the event in honor of the Maccarone Family. The Maccarone's from Syosset, New York were the driving force behind this special day. John Maccarone was recently named to the CRN Board of Directors. Marybeth Kruppenacker and Jose Morales, CRN Board Members, also attended the event to lend their support.

The day began with registration and a buffet breakfast and then a beautiful day of golf on a picture perfect Fall day in New York. The evening's fabulous surf and turf dinner was highlighted by our keynote speaker, Dr. Frederick J. Kaskel, Director of Montefiore Children's Hospital-Pediatric nephrology and Ira Greifer Children's Kidney Center of the Bronx. Marybeth Kruppenacker thanked the organizers of the event, Joe and Diana Kaufman, for all of their efforts in making the day so wonderful. She also thanked the entire Board of Directors of the LIPCA for their incredible support and generosity. Dr. Kaskel, Marybeth and Jose Morales were each presented with a plaque for their work with CRN. The evening culminated with CRN receiving a check for \$50,000. The LIPCA were very happy to support the cause and announced plans to do the same next year.

The Long Island Plumbing Contractors Association is an organization of unionized plumbing contractors, affiliated with United Association Plumbers Local #200 for the common benefit of exchanging ideas and solutions to business problems of the unionized construction industry. Many thanks to our golf chairman, Mr. George Luksch of Seaford Avenue Plumbing for this year's successful event. John Maccarone served as Co-Chairman of the event.



Jack Greeley's 9th Birthday Letter



Jack Greeley with dad, Dave

The Greeley Family of Chicago, Illinois has reached out to family, friends and colleagues for the seventh year and asked for donations to be made to CRN in honor of their son Jack's 9th birthday on March 17. The Greeley's have raised over \$140,000 with their letter campaigns, with this year's letter raising nearly \$15,000.

The theme of this year's letter focused on the increasing variety of challenges Jack and his family face as he grows older in regards to not only his medical issues, but also social and other school related obstacles:

"One of the beauties of sports is that they act as metaphors for life. For our son Jack, his first experience with fast pitch baseball last summer was no exception. As a third grader facing a menacing, flame throwing fourth grader, Jack did not get out of the way of a pitch and got plunked in the chest, leaving a healthy welt. Jack was displeased to say the least, plus his remaining season was effectively over, since he tried to hit each pitch standing about three feet away from home plate.



Christy, Dave & Jack Greeley

Jack had an important lesson reinforced that day, literally; when life knocks you down, you need to get back up, dust yourself off, and take another swing. How will he respond this season? It is tough to say, but "getting back up" is something that Jack has done quite a bit of over the past eight years when, just after his first birthday, March 17, 2001, he was diagnosed with Cystinosis (www.cystinosis.org), a chronic, life threatening metabolic genetic disease. So, while a pro ball career is not in Jack's future, the good news is that Jack does have a promising future, which was not always necessarily the case."

Read more from this year's inspiring letter by visiting the CRN website under Events/Fundraisers.

Kenadee Julian's friends & family raise money for CRN

By: Dan Julian



Kenadee starting the race with friends & family

On March 21, we held our first 5k run/1 mile walk to raise money for CRN. With the help of our friends and family, we were able to raise a little over \$30,000. We were blessed to have about 200 runners/walkers on a chilly, brisk Saturday morning. Immediately following the race, we held a luncheon and a silent/live auction. The outpouring of love and support was phenomenal. So many people gave so much of their time and talents to make this day a huge success.

A member of our church family owns a dance studio, Kinner & Co. She and her husband held a dance recital and moscatolli dinner on May 17. All the proceeds went to CRN in honor of Kenadee Julian. We were able to raise \$5,100. We are so thankful and blessed that Kathy and Dave Kinner held this special event to raise awareness about cystinosis in our community and helped to support the efforts of CRN.



Dr. Korine Vlahos & Kenadee Julian

Miracles at Milleridge Dinner raises over \$29,000 for CRN

By: Marybeth Krummenakcer

The 4th Miracles at Milleridge Dinner Dance was another successful event which benefited the Cystinosis Research Network. Once again, there were over 300 people in attendance for this wonderful evening and a special toast was made to Laura Krummenacker who was celebrating two special anniversaries.....20 years since diagnosis and 10 years post kidney transplant! The evening progressed with music, dinner, dancing, raffles and more and all in attendance would agree that a fabulous time was had by all!



Laura Krummenacker and friends at Miracles at Milleridge Dinner Dance



Tahnie Woodward, Laura Krummenacker & Shea Hammond

The families in attendance were, Krummenacker, Finn, Woodward, Hammond, Morales and Greeley Families and all would agree at what an amazing experience it was. The true beneficiary of this amazing event was CRN --- as over \$29,000 was raised that evening. We are pleased to announce that the 5th Miracles at Milleridge will be held March 13, 2010!

Long Island Chef's Golf Outing raises over \$15,000 for CRN

By: Marybeth Krummenakcer

The Long Island Chef's golf outing was held on August 10, 2009 at the Sands Point Golf Club in Sands Point New York. The Binder family truly stepped up to the "tee" and did an amazing job with the help and support of their good friend Chef Rob Hamburg. The day began with a buffet breakfast and then a wonderful day of golf. The event ended with a buffet dinner prepared by extraordinary chefs from some of the premier restaurants on Long Island. There were also terrific raffle prizes and a 50/50 raffle. Most importantly, it was a wonderful evening of good food and good company. At the end of the day over \$15,000 was raised for CRN.



Fifth Annual Jack's Family Fun Day Raises Over \$15,000

By: Christy Greeley



The Ellerbrock Family



The LeBeau Family
with Jack Greeley

The Fifth Jack's Family Fun Day took place on October 18, 2009. The event was a Fall Festival held at Tamarak Country School and Day Camp in Lincolnshire, Illinois to benefit CRN in honor of Jack Greeley. After a very rainy and cold October in Chicago, the skies parted and we were blessed with a perfect, sunny Fall day! Nearly seven hundred people enjoyed a variety of activities including pumpkin decorating, hayrides, pony rides, a balloonist, face painting, arts and crafts, silent auction, bake sale,

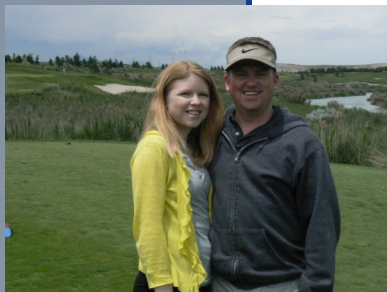


cake walk, music by Charizma, basketball, games with prizes, moon jump, soccer clinics led by Chicago Fire players with autographs, and an appearance by Sparky the Chicago Fire Mascot. The event this year was a great success, raising over \$15,000. The five Jack's Family Fun Days have raised approximately \$80,000 for CRN. This event is run entirely by volunteers, with nearly all of the services and entertainment donated by local businesses and sponsors. We cannot thank our friends, family and community enough for their support!

3rd Annual C.H. Robinson Golf Tournament Raises Over \$41,000

By: Tahníe Woodward

The 3rd annual C.H. Robinson Golf Tournament to benefit CRN in honor of Tahníe Woodward, was held Saturday, June 13th, 2009 at Thanksgiving Point in Lehi, Utah. Even up against the threatening thunderstorms that caused us to end the golfing early, we were able to raise an amount that is a new record for this event; over \$41,000 for CRN! It was a fun filled day full of people willing to help and donate their time; even the less than ideal weather couldn't put a damper on any of it. The experience of loved ones and strangers coming together to support Cystinosis Research, even in this economy, was truly unforgettable.



Tahníe Woodward
& Rory Boyer

Extra special thanks are due to Kevin and Ev Kofford, Rory Boyer, Kory and Robyn Kofford, and Mikjen Cassidy for going above and beyond to help make the day a success! To make it even better, the 4th annual C.H. Robinson Golf Tournament for CRN will be held June 12th, 2010!



TEAM KACY—Wyman Family Fundraising

By: Jen Wyman

We continue to be amazed by the outreach of our community! To follow our theme of the conference we have to say that, once again, our family and friends have gone Above and Beyond for us.

Kacy shows us time and time again that she is a tough, determined, and resilient little girl. Our community of supporters have become our TEAM KACY! They cheer us on, support us endlessly, and create a warmth in our hearts that I hope everyone feels in their lifetime.

BOWL for a CAUSE

Our 2009 fundraising year began with a second bowling event put on by Kacy's Uncle, Troy Wyman. His entourage of friends and family raised \$2300 for CRN.



Tim, Kacy & Jen Wyman

STASH 4 CASH and READ-A-THON

6th Grade Student Leadership under the guidance of Mrs. Turowski, raised \$2,700 for the Cystinosis Research Network. Student Leadership learned about Kacy's disease from big brother Jack, brainstormed ways to raise money and decided on a Read-a-Thon sponsorship in addition to the donations for Patrick Berry's mustache growth. The deal was that Mr. Berry (6th grade teacher) would grow it for an entire marking period. People from all over the community sponsored students IN A SCHOOL-WIDE EFFORT, to read a set number of books and contribute to the lip hair. The grade that raised the most money had a special treat at the end of the fundraiser ...the sixth graders gathered in the cafeteria in the a.m. and cut off the stache in a manner of their choosing. They chose to leave half of it and Mr. Berry sported a "half-a-stache" the rest of the day.



Kacy Wyman at ACES event

PAY IT FORWARD PROJECT: ACES

Conant Elementary (Kacy's school) held a Pay it Forward event called ACES (All Children Exercising Simultaneously) For every 1/10th of a mile that they walked/ran they collected a penny (of which came from a Penny Race Collection a few days before). Children then took their earned pennies and chose different charities to donate to. CRN was one of 4 charities that benefited from the event. \$131 more came our way.

CYSTITINOSIS 5K RUN/WALK

May 3, 2009 was our Third Annual Cystinosis Fun Run. For the third year we had gorgeous weather and a record turn out of runners and walkers. It is a remarkable thing to see over 300 people come out to honor Kacy and others who are living with Cystinosis. It's even MORE remarkable that we know most of them personally. We will continue to hold this event for years to come. This year's 5K raised \$15,000 for CRN.



Tim & Kacy Wyman

SUMMER SOLSTICE BEACH PARTY

June 19 our unbelievable neighbors and friends-W.I.N. group (Women in the Neighborhood) came together to throw a Summer Solstice Beach Party to honor Kacy for yet another year. I have never met a more determined group of people. They go all out to put on the best event they possibly can. We had a horrible forecast, but as party time approached the skies cleared (however briefly) for all of us to gather. Not long after Mother Nature unleashed the storm of all storms on us. The party comprised of 60 people standing under 4 tents for 5 hours, surrounded by water in the worst electrical storm of the year. And...we had a BLAST!!!! \$6000 and a week's worth of drying out left us with memories that will last a lifetime.

Upcoming Fundraisers: November 6, 2009—Senior Tennis Mixer in Dearborn, Michigan. Hosted by the Dearborn Racquet Club and Kacy's Grandma, Cindy Pena. Fun Run is tentatively set for Sunday, May 1, 2010.

Lori Horton, close friend of Jen Wyman's and jewelry designer, has created a stamped disc charm with the CRN logo on it and the heart charm that Kacy Wyman (7, with Cystinosis) chose to honor all people living with cystinosis. The charms can be worn as a bracelet or as a necklace. A portion of the proceeds will go to the Cystinosis Research Network.

CYSTINOSIS BRACELET / NECKLACE

ORDER FORM

(\$10.00 per bracelet/necklace will BENEFIT the Cystinosis Research Network in honor of Kacy Wyman)



Pictured charm is a 12mm sterling silver disc that is hand stamped with the CRN puzzle logo, oxidized, and individually polished.

The open-heart charm is also sterling silver and was especially selected by Kacy Wyman.

Charms only - \$20.00 _____

Bracelet (measure wrist) - \$25.00 _____

Necklace (16" or 18") - \$30.00 _____

Waxed linen cord (double or triple strand): Black _____ Brown _____
 Waxed cotton cord: Black _____ Brown _____
 Red _____ Light blue _____
 Light green _____ Pink _____
 Purple _____ Yellow _____



Sterling chain-Additional charge _____

Name: _____

Address: _____

Phone: _____ Email: _____

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(248) 667-8198 or visit www.simplybdazzled.com



Place an online order through goodshop.com and raise money for CRN!



See page 30 for more details!



Join the Cystinosis Research Network

Get connected! Stay informed! Together we can find a cure!



Jimmy, Dawn & Adam Yearwood

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

CRN provides outreach and access to resources. We take great pride in carrying out our motto:

"Dedicated to a Cure. Committed to our Community"...whether you are ...

- A **Parent** who needs critical resource information, support services or help in sharing the challenges of cystinosis to those who serve your child.
- An **Adult** with cystinosis interested in information regarding medical and social issues that are specifically geared for adults.
- A **Relative** or a **Friend** who wants to increase their understanding of cystinosis and find out how you can help out or become involved.
- A **Physician, Social Worker, Educator** or other **Professional** who makes a difference in the life of a family affected by cystinosis, and want to have access to critical information to better serve your patient, student or client.

Joining the Cystinosis Research Network enables you to:

- Receive all the latest cystinosis information through our countless resources, including the biannual CRN Newsletter, our very informative web page www.cystinosis.org, the popular online Cystinosis Support Group, and our toll free number (1-866-276-3669).
- Attend the CRN Family Conference with other cystinosis families to exchange knowledge and create friendships. Also, find out the latest discoveries about cystinosis from the medical professionals.
- Let your voice be heard by legislators and policymakers who need to know why cystinosis (and other rare diseases) are important issues to you.
- Have access to the Cystinosis Research Network's representatives in the areas that are most relevant at any given time to you or your loved one affected by Cystinosis.

Join the Cystinosis Research Network today!

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

Cheri Friend

VP Family Support, Cystinosis Research Network



Jim & Melea Martin

Join the Cystinosis Research Network today!

Immediate Family.....\$20.00
 Extended Family/Friend.....\$25.00
 Professional.....\$35.00

International: (Including Canada) Base rate—see categories above, plus \$10.00 for postage. Payable in US dollars.

Please complete this form & mail it with your check payable to CRN to:

Cystinosis Research Network
 302 Whytegate Court
 Lake Forest, IL 60045

Name _____

Street _____

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Phone _____ Fax _____

Email _____

Name of Child / Adult / Acquaintance / Patient affected with Cystinosis:

CRN Support Groups

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

The CRN Support Groups are an easy way to communicate with the cystinosis community using Yahoo Groups. Yahoo Groups are a way of communicating by email to many people that belong to the same group.

CRNSupportGroup and **Cystinosisteensupport** are the two cystinosis Yahoo Groups affiliated with the Cystinosis Research Network.

- ◆ **Cystinosis Support List (CRNSupportGroup)** - 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 with it, vent our frustrations, share our fears, our hopes, and dreams.
- ◆ **Cystinosis Teen Support List (Cystinosisteensupport)** - 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 included questions, concerns, ideas and supportive sharing.

If you would like to subscribe to either of these lists, please visit the CRN website at www.cystinososi.org or contact CRN at crn@cystinosis.org or 1-866-276-3669.



Bree Forrester

Please Support CRN's Mission with Your Donation

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

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

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In Honor Of _____

In Memory Of _____

You may send notification of my gift to:

Please check all that apply:

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_____ Individual with Cystinosis

_____ Parent of Child with Cystinosis

_____ Professional

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_____ I am interested in volunteering for

Search the Internet Using GoodSearch and Raise Money for CRN

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

To get started, go to www.goodsearch.com. Be sure to select "Cystinosis Research Network" where it says "Who do you GoodSearch for?" Then search like you normally would! It costs you nothing.

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

Make Online Purchases using GoodShop and Raise Money for CRN

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

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

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





United Way Contribution Guidelines

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

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

The local United Way organization will contact The Cystinosis Research Network via phone, fax, or e-mail to request we prepare and submit documentation verifying our status as a non-profit organization.

The Cystinosis Research Network prepares all necessary documentation and submits it to the respective local United Way organization.

The local United Way organization processes the documentation and sends a check for the aggregate sum designated for the Cystinosis Research Network.

The Cystinosis Research Network sends thank you/acknowledgement letters to recognize contributing individuals.

Buy Cystinosis Research Network Fun Stuff!

In partnership with Café Press, the Cystinosis Research Network is pleased to offer shirts, hats, mugs, buttons, bags and many other items that sport our logo.

More importantly, 15% of all purchases go directly to CRN.

Your purchase serves to support our fundraising efforts and also to create awareness by "wearing the brand". Clothing and accessories are great to wear to cystinosis fundraisers.

Access the CRN Store at:

<http://www.cafepress.com/cystinosis>

Shop til' your heart's content, and be sure to tell your friends and family!



Donate to CRN by Selling on eBay

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

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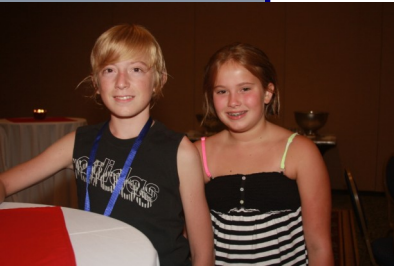
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Editors: Paula Shal and Cheri Friend

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

CRN Vision and Mission

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

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