



Jeff and Nancy Stack

Dear Friends *continued from front page*

We are proud to report that 100 percent of all donations are used to support medical research. To all who attended the event and the many others who made contributions, we thank you for your support and generosity. Jeff and I continue to be amazed at how fortunate we are to have such a wonderful community of family and friends. We cannot thank you enough for your support in our efforts to find better treatments, and ultimately a cure for Cystinosis.

We are also gratefully to the many volunteers who made our *Natalie's Wish* event such a success. We are especially thankful for the tireless efforts of Zoe Solsby, Marylyn Milburn and Vince Ciavarella.

Your financial support, good wishes and prayers have provided Natalie and others with Cystinosis the hope they so desperately need. We are eternally grateful for your friendship and your commitment to our cause. We are continually reminded of how blessed we are to have each of you in our lives.

We hope you will join us for this year's *Natalie's Wish* event on Thursday, May 20 at The Clubhouse at Pelican Hill in Newport Coast. The event, which promises to be as uplifting as last year's, will begin at six with wine and hors d'oeuvres, followed by a research update, entertainment and *Fund-A-Cure*.

Tee Off For A Cure

Through the efforts of Vince Ciavarella, the Building Owners and Managers Association (BOMA) of Orange County will host a Charity Golf Tournament and Auction to benefit the Cystinosis Research Foundation. The tournament will take place on Monday, May 17, 2004 at the Mile Square Golf Course in Fountain Valley.

Vince proposed the Cystinosis Research Foundation (CRF) as the charity for this year's tournament. After viewing the CRF video and hearing *Natalie's Wish* CD, the committee whole-heartedly embraced the foundation.

We are asking individuals and businesses to support this event by signing up to play in the tournament, by attending the awards dinner and auction, or by providing an item for the silent or live auctions. If you would like information, please contact Mike Raring, of The Lighting Company at (714) 936-3012. One hundred percent of all proceeds generated at the auctions will go to the foundation.

Founded in 1907, The **Building Owners and Manager Association** of Orange County, is an international federation composed of more than 15,000 members representing all facets of the commercial real estate industry.

Mylan Laboratories: *Purveyor of Hope*

Cysteamine, the only drug that slows the progression of Cystinosis by removing the cystine from the cells, was designated an "orphan drug" as defined under the Orphan Drug Act of 1983. In 1992, Mylan Laboratories Inc. assumed responsibility for developing cysteamine in capsule form. In 1994, the new product, called Cystagon®, became available to the children and young adults with Cystinosis.

The introduction of Cystagon®, greatly improved the quality of life for those who suffer from Cystinosis. The cystinosis community greatly appreciates Mylan's commitment to this orphan disease.



I wish I may, I wish I might, have the wish I wish tonight.

CYSTINOSIS RESEARCH FOUNDATION

18802 Bardeen, Irvine, California 92620
949.809.2418 • www.natalieswish.org
501(c) 3 Federal Tax ID #32-0067668

PRESORTED STANDARD
U.S. POSTAGE
PAID
SANTA ANA, CA
PERMIT NO. 3

Save the Date

THE THIRD ANNUAL
"NATALIE'S WISH" FUNDRAISER
THURSDAY, MAY 20, 2004
THE CLUBHOUSE AT PELICAN HILL
NEWPORT COAST, CALIFORNIA

Natalie's Wish

*Star light, star bright,
First star I see tonight
I wish I may, I wish I might
Have the wish, I wish tonight.*

FOR FRIENDS OF NATALIE STACK AND SUPPORTERS OF THE CYSTINOSIS RESEARCH FOUNDATION ★ SPRING 2004



From Natalie

- ❖ *I have a rare disease called Cystinosis. This disease*
- ❖ *has affected my life in many ways. It has brought*
- ❖ *me good things and bad things in my life.*

The bad things about Cystinosis are taking my medicine every six hours, waking up at night to take my medicine and not growing as tall as I would like. Even though I have this disease and it is not what I want, it has made me a better person. I know what other people with diseases have to suffer through because I have one too. I also think that I am a more sensitive person because of my disease. Cystinosis has brought my friends together and my family together.

I wish my disease would go away forever.

Since I have this disease, my parents have held a fundraiser every year for me and other children with Cystinosis. They are trying as hard as they can to find a cure for all of us so that we can be like everyone else and not take medicine all of our lives, and so that we can sleep through the night. My parents have raised a huge amount of money for doctors who are trying to cure this disease.

Thank you for giving us money for the research. Every bit helps. Each dollar gets us a step closer to finding the cure. I have wonderful friends who support me every day and I know that I am very lucky.

I am also thankful to have such an incredible loving family including my sister, Alexandra, who always makes me feel better when I am blue. She is very special to me.

I hope one day I will feel good and live even longer. With everyone's donations, I am sure that the cure will come soon.



Natalie and her closest friend and sister, Alex

Welcome to the premiere issue of **Natalie's Wish**. It's the first newsletter devoted to the people, news and events that have contributed to the growth and mission of the Cystinosis Research Foundation: to find more effective treatments, and ultimately a cure for Cystinosis.

Dear Friends,

In February 2003, on Natalie's 12th birthday, she shared her secret wish with me: "to have my disease go forever." At our second annual fundraising event, on May 28, 2003, her wish moved closer to becoming a reality.

This remarkable evening began with an overview of Cystinosis presented by Dr. Ranjan Dohil, a Pediatric Gastroenterologist at The University of California, San Diego. Among other things, Dr. Dohil explained what cysteamine, a drug given to Cystinosis patients, does to the intestinal system.

After Dr. Dohil's presentation, Vince Ciavarella, a family friend, and a gifted group of musicians and vocalists sang a special song for Natalie. The song, written by Vince, was titled **My Wish**.

The highlight of the evening was an emotional video featuring Natalie and several of her friends who also have Cystinosis. The evening culminated with a **Fund-A-Cure** round of donations totaling \$87,000. The large amount raised during **Fund-A-Cure** was driven by a generous matching gift challenge of \$25,000 from Mike and Lynette Hayde. By evening's end more than \$325,000 had been donated. Additional gifts have continued to come in. To date, over \$410,000 has been raised as a result of this special evening.

This support has allowed us to fund multi-year studies, something that has been impossible in the past due to lack of long-term funding.

continued on back page

Nathan's FIRST BIRTHDAY

Renee Carter, Nathan's mother shares her thoughts on Nathan's first birthday:

In planning Nathan's first birthday party, Daryl and I agreed that we did not want it to be a "big deal"; however, when the invitation list was complete, there were 92 people on it!



Knowing our friends and family, and their propensity towards generosity, our first thought was to request "no gifts." Nathan, at one year of age, already has more toys than he can play with and more clothes than he can wear.

As we talked about the party, we realized that our request for "no gifts" would probably go unheeded. Nathan would undoubtedly receive many gifts. Still, we did not want his party to be about presents. It was intended as a celebration of life, and truly as a thank you to all of our friends and family for their support during our first year of parenthood.

It was then that Daryl asked, 'Why not suggest that if people feel compelled to give Nathan something, they make a donation on his behalf to the Cystinosis Research Foundation.' We immediately knew this was the perfect solution—and one that would enable us to celebrate not only Nathan's life, but the life of our dear friend, Natalie Stack as well. On the invitation we stated, 'We believe the best gift we can give our son is the disposition to share the blessings of his good health and good fortune with those who are not as blessed.' Our request for no gifts was respected and the party was a wonderful success.

We thank Renee and Daryl Carter for sharing Nathan's first birthday with us and the Cystinosis Research Foundation. The Carter's friends and family raised more than \$1,400 for the Cystinosis Research Foundation.

Research Updates

Cysteamine Absorption Study

As a direct result of the May, 2003 fundraiser, the Cystinosis Research Foundation (CRF) was able to fund a two-year study by Dr. Ranjan Dohil.

Dr. Dohil is an Associate Professor of Pediatric Gastroenterology at the University of California, San Diego (UCSD). After receiving approval from the Human Subjects Committee at UCSD, and the Food and Drug Administration, the study commenced in November, 2003. The first patients to be studied as part of the control group had to be over 18 years old and healthy. To date, three patients have successfully completed the study and three more have been scheduled. Dr. Dohil must also enroll six Cystinosis patients for this study. The first of these patients will be studied in late February and early March of this year. Natalie is scheduled to be part of the study in mid-March.

Cysteamine, a drug that is imperative for the survival of children with Cystinosis, needs to be taken every six hours for the rest of the patients' lives. This rigorous schedule coupled with the drug's powerful side-effects result in poor compliance for the drug. The purpose of the Cysteamine Absorption Study is to evaluate the absorption of cysteamine in the intestinal tract. The hope is to create a new way of delivering the drug, thereby optimizing intestinal absorption, reducing frequency of drug administration, and ideally, diminishing adverse gastrointestinal side-effects.

Dr. Dohil comments, "Cystinosis is a life-threatening disease, but, as with any rare condition, funding research is difficult. The efforts of the CRF have been unbelievable, and have allowed us to carry out studies that would not have been possible otherwise."

Adrian Corbiere
Drs. Craig and Susan Cox
Douglas Crocker, II
Marcus and Kim Cubeiro
Arthur Danielian
Daniel and Judy Daniels
Thomas and Molly Davin
Steven and Deanna Dawson
Dr. Steven and Sheila Dennis
Peter and Susan Denniston
Emmett Ebner
David Emmes and Paula Tomei
Howard Englander
Jeffrey and Patti Estabrooks
Dale and Gail Fasse
Charles Favreau
Charles and Nancy Fry
William and Marcia Gaboury
Daniel and Rosalie Gee
Tammy Glaser
Alan Greeley
Robert and Risa Groux
Chuck Groux and Dave Taborelli
Bruce Hallett
Jeff and Susan Hamar
Bob and Katrina Hamilton
Harbor Day School Faculty Fund
James and Mary Harrington
Terry and Sharon Hartshorn
Jeff and Shana Hill
Barry and Cinda Hoeven
David and Linda Jacobson
James and Merrins Jones
Gary Kachadurian
Harry and Joan Karsten, Jr.
Charles and Valerie Kircher, Jr.
Roger and Gail Kirwan
Gerald and Barbara Kleinman
John Kobierowski
Simee Kristjansson
Dr. Andrew and Vickie Lazere
Steve Longo
Eric Luna
Dominic and Francine Magliarditi
Alison Malkhassian
Christopher and Pam Massey
Kevin and Deborah McKenna
Sally McManus
Charles and Anna Mentas
Todd and Erin Meyer
Anthony and Melinda Moiso
Peter Montgomery
Ronald Morgan
Vicki Mullins
Rick and Diane Nelson
Richard Ortwein
Marc Pinto
Falise Platt
Jodi Rios
Mark Ritchie
Joseph Robert, Jr.
Mike Roos
David and Kathleen Rosenberger
Drs. Jerry and Elaine Schneider
Kent and Nancy Snyder
Col. Ray and Mari Snyder
Ygal and Sheila Sonenshine
Ken and Lynda Stack
William and Terri Stampley
William Steele
David Team

John and Nina Townsend
Branden Turnball
Dr. Elliott and Barbara Wagner
Chris and Laurie Wall
Jeffrey Weber
Peter Welsh
Russell Werdin
Carl and Beverly Willgeroth
Michael and Roberta Winer
Michael and Julie Winter
Eric and Cynthia Wittenberg
Gary and Lori Wright

\$100 AND MORE

Hank Adler
Jeffrey Allen
Donald Anderson
Dick Austin
Russ and Debbie Bartlett
Elliot and Randi Beckley
Harold and Hinda Beral
Daniel and Lynda Bibb

Natalie is a trooper. Her resolve and fortitude in the face of such an unknown and frightening future is truly heartening and humbling. It strengthens our efforts to make that future better.

Jess G. Thoene, MD, Director, Hayward Genetics Center,
Tulane Health Sciences Center, New Orleans, Louisiana

George and Wendy Bigelow
Kenneth Bohan
Stephen and Cynthia Brahs
Theodore Broedlow
Lee and Diana Bromiley
Robert and Kathleen Brunswick
Scott and Jody Burnham
Richard Burns
Kenneth and Julie Busch
Howard and Karen Campbell
Terrance and Melinda Casey
Michael and Christa Christ
Michael and Pamela Coleman
David and Shelah Combs
Brian and Kate Corrigan
Allen Court
Jack Cuneo
Thomas Curran
James and Lois Dailey
Mary Frances de la Pava
Marc DeBaptiste
Al DeGrassi
Maurice and Carolyn DeWald
Peter DiCorpo
Karen Dimmick
Mark and Ann Donlon
Scott Doyle
Dr. Sidney and Renee DuPont
Raymond Eldridge, III
Barbara Emmons
Steven and Stacie Epcar
Brian Fargo
Stephen Finn
Marcus and Natalie Fitzpatrick
Joanne Fix

Dr. Scott and Marjorie Forman
Nadyne Foster
Stephen Furnary
Patrick and Bonnie Fuscoe
Michael and Joan Galvin
Dr. Richard and Margaret Garbe
John and Carolyn Garrett
Gary and Sarah Geuss
John and Linda Goodman
John Goodman and Laurie Effron
Richard and Cecilia Goodman
David and Robyn Grant
Stephanie Graves
Leonard and Beth Griffiths
GSCOC Brownie Troop #1095
Ellen Guccione
Harbor Day Teachers
Michael and Donna Heiken
Michael and Kristin Heusses
Dave Hoffman
Timothy Hogan
David and Linda Holmes

Timothy Holzheimer
Louis and Jennifer Hoyes
Scott Ingraham
Ted Inouye
Robert Jennett
Guy and Debbie Johnson
Judy Johnson
Robert Johnston
Richard Kadish
Col. John and Deralyn Kaheny
Shawn and Kathy Kelter
Cassie Keturakis
John and Anne Kittleson
Kristen Klingbeil-Weis
Tom and Bethany Knapp
Kevin and Lesly Knight
Jon Knorpp
William Krauch
Roland Kyle
Salvador Leccese
Sharon Lee
Lewis Levey
Lawrence and Sandra Lewis
Darla Longo
Gregory Lozinak
Larry and Cindy Lukanish
Andrew and Claire Mackay
Donald MacKenzie
Lt. Col. Justin and Sandy Martin
Thomas and Mary McManus
Ronald and Kathryn Merriman
Dwight Merriman
Marylyn Milburn
Scott and Marilyn Monroe
Saraellen Moore

Timothy Moriarty
Karen Muller
Patrick and Martha Murphy
Carl Neuss
Stephen and Suzy Palmason
John and Betty Parker
Michael Parnell
Stephen Paulin
Tom and Barbara Peckenpaugh
Dr. Richard and Doreen Penfil
James and Stephanie Pugash
Stephen and Stephanie Rados
Thomas and Maya Redwitz
Ron and Mary Richmond
Gerald and Carie Ross
Peter and Janie Rothschild
John and Kristin Rowe
Robert and Ann Ruocco
Andrew Schor
Gary Schwandt
David Schwartz
William Shattuck
Todd Shaw
Bayle and Alison Smith
Steven and Stacie Spitzer
Katie Stack
Robert Stemler
Brian Stoffers
Marty Stolzoff
Timothy and Susan Strader, Sr.
David Strong
Bethann Sullivan
James and Leslie Sullivan
Cory Thabit
Bart and Deborah Thomsen
Dr. Doris Trauner
Paul and Melinda Trevino
Laurie Truman
Louise Upham
Kenneth Valach
Richard Van Wert
Frederick and Anne Waldeck
Marc Weinberg
Robert Whyte
Ronald Witten
Dr. George and Lois Wolfe
Steve and JoLynne Woo
Donald and Mary Beth Woods, Jr.
Kelley and Heidi York
Drs. Richard and Elissa Zelter

LESS THAN \$100

Donald Abrams
Jean Anderson
Deborah Anderson
Daniel and Jean Ardell
Dr. Gary and Linda Bennett
James and Mary Buckingham

Judy Burns
Kimberly and Robin Canada
Linda Carter
Philip and Linda Chenok
James and Pam Conner
Ken and Lily Cooper
Caroline Cosgrove
Michael and Diane Costanzo
Raymond and Margaret Cully
Matthew Edmondson
Dr. Elliott Fankuchen and
Dr. Lisa Kantrowitz
William and Susan Finn
David and Margie Fischer
Wesley Jones and Rebecca Flynn
Brian and Lynn Freeman
Steve Gilmore
Fred and Olivia Glennon
Lawrence Gray
Harbor Day School
Mrs. Taylor's Second Grade
Larry and Michelle Harmsen
Nolan and Susan Harrison
Stephen and Christina Hogan
Rick and Juliette Hume
Bennett and Kathleen Jackson, Jr.
Andrew and Olivia Johnson
Kevin and Margaret Johnson
Terry and Maryann Jones
James and Lavonne Koehler
Robert and Joanna Ladd
Robert and Michelle Liset
Wayne and Carolyn Lytle
Karen Mason
Bruce and Mary McDonald
Bruce and Ellen Miller
Marvin and Dr. Julie Miller
Karen Mitchell
Erin Morahan
Leonard Moskovits and
Jennifer Rodriguez
Michael Mueller
Mark and Kathleen Peterson
Lt. Col. Ken and Sharon Pipes
Vincent and Shannon Pozzuoli
Christopher and Lizette Pribus
Sandra Ryan
Robert and Suzanne Searles
Leslie Shattuck
Sarina Sherwin
Alexandra Stack
James and Marjorie Stanzel
Olive Stephens
James and Cheryl Taylor
John and Lynette Vieira
Eugene and Ann Wolff
Steven and Debra Yamanoha
Peter Zacar

We have attempted to include every donor on this list.
We apologize for any errors or omissions. Please contact
Marylyn Milburn at (949) 809-2418 if we have
listed you or your donation incorrectly.

We deeply appreciate your support.



Natalie Stack as featured on the front cover of Mylan Laboratories 1995 Annual Report

Did You Know...

Cystinosis afflicts approximately 500 people, mostly children in North America, and less than 2,000 worldwide. It is a rare genetic disorder that causes cystine to accumulate in organs. Cystine is trapped in the cell and forms crystals causing cell death as its concentration increases. The crystals slowly destroy organs in the body including the kidneys, liver, eyes, muscles, thyroid, white blood cells and the brain.

Daily life is painful for children with Cystinosis. Cystine crystals cloud Natalie's corneas causing photophobia, and she experiences joint pain likely caused by rickets. A twenty-four hour craving for water causes permanent stomach distention and frequent urination. Natalie suffers from constant, severe abdominal pain caused by the powerful drugs she must take to stay alive. Cystinosis is also characterized by Fanconi Syndrome, a rare kidney disease which eventually leads to end-stage kidney failure and kidney transplant. Transplants and drug therapy have improved the life expectancy of these children but other complications arise that include swallowing difficulties, visual impairment, diabetes and central nervous system involvement.

There is no cure for Cystinosis, but there is hope. Unfortunately, Cystinosis affects so few people that research money is scarce and progress is slow.

There are over 6,000 rare or "orphan" diseases in the United States. An "orphan" disease as defined by the Orphan Disease Act affects less than 200,000 people. Collectively however, these diseases affect more than 25 million Americans.

While there are only a small number of patients who suffer from any given "orphan" disease, knowledge discovered by studying one disease may lead to advancements in other rare diseases and more prevalent and well known disorders.

For more information about "orphan" diseases" visit www.rarediseases.com.

Donor List *continued from page five*

\$2,500 AND MORE

Gerson and Barbara Bakar
Camden Property Trust
Vincent and Sarah Ciavarella
Ralph Eidem, Jr.
William and Kathleen Esser
Stanley Fimberg
James and Heidi Harper, Jr.
Harold Hofer
Institutional Housing Partners
John and Janice Markley
Joe and Lori McKay
Norman and Suzy Metcalfe
O'Malley and Ann Miller
Bernie and Janet Schneider
Jim and Janet Stoneman
William and Christine Thormahlen
Wells Fargo Bank
Arn and Nancy Youngman

\$1,000 AND MORE

Agly Foundation
Anthony and Ginger Allen
David Ash
Bank of America
Arthur Barrett
Philip and Shelley Belling
Kelley Bergstrom
Blake and Jill Berteau
Bluestone Communities
Brady Communications, Inc.
David and Judy Breitstein
Preston and Carolyn Butcher
Churchill Mortgage Corporation
Jerome and Barbara Claeys, III
Robert and Anne Marie Coughlan
Richard and Kimberly Crawford
Creative Design Consultants
Greg and Victoria Currens
James and Jennifer Damon
Bruce Duncan
Richard Eddy
Franciscan Friars of the
St. Barbara Province
Freddie Mac Foundation
Richard and Debbie Gebhard
Edward Geraghty
Michael and Elizabeth Gill
Donald and Sonja Grant
Stan Harrelson
Dean and Barbara Henry
Lawrence and Dee Higby
Mark and Susan Hillgren
Bradley and Lisa Hillgren
Allan and Sherry Hunter, Jr.
Michael Jeffers
JH Snyder Company
Roy and Gayle Jones
KB Homes
Darby Keen
Keybank
KFM Financial and Ins. Services Corp.
Michael and Kathleen Kiley
Mary Ann King
Dr. Dale Kistler and Dr. Sue Murahata
Harvey and Vanida Ludwig
Victor MacFarlane
Paul Makarechian
Dr. Howard and Rachel Marans
David E. Martin, AIA
William and Kathalayne McCullough

Gary and Carolyn McKitterick
James and Oralee McNamara
Kim Megoigal
Meredith, Weinstein & Numbers
William Millichap
Michael and Ann Moorhead
Thomas and Susan Moran
Jeffrey and Margie Morgan
Michael and Ellen Morrell
Morrison & Foerster Foundation
Donald Morrow and Judy Johnson
Douglas and Donna Neff
Richard and Chrissy Nicholas
Augie and Lynn Nieto
James and Beverly Peters
Previti Family Foundation
Brian and Linda Prinn
RAP Communications
Peter and Mary Rooney
Anthony and Marie Rossi
John and Kathleen Schaefer
John Scherer
Dennis Schmucker
Shea Homes/Shea Properties
Stephen Silk
Alex Spanos
Jeffrey and Stacy Stone
Les and Ellen Thomas
Michael Trapani
Larry Tucker and Jill Johnson-Tucker
Ueberoth Family Foundation
Kent and Virginia Valley
Cathy Voreyer
James Warmington
James and Kimberly Watson
Marcus and Ann Winthrop
Stephen Zotovich

\$500 AND MORE

Allen Charitable Lead Annuity Trust
Frederick Allen
Jon and B.J. Anderson
Anonymous
Hugo and Irene Aviles
Bruce and Diane Bearer
Dr. Stephen and Sandy Bell
Dr. Alan and Lesley Beyer
Douglas and Lorraine Bibby
Dr. Charles and Lan Bolus
Clark Booth
C.C. Pascal Family Partnership, L.P.
Craig Cadwalader
Wayne Call
James Callard
William and Linda Campbell
John and Susan Campbell
Christopher Homes
Carol Cranfield
CST Environmental, Inc.
Terrance and Courtney Daniels
Sean Deasy
Timothy and Angela Donahoe
Eagle Construction
Richard Emsiek
Daniel Epstein
Dr. Edward and Patti Feldman
Fidelity National Title
Eric and Jill Flyckt
Force Framing
Frank and Jan Foster
Richard Foster

Gamespy Industries, Inc.
Ben Gifford
Richard Glucksman and Lori Sklar
John and Judy Goolsby
David and Ruthy Green
John and Kathy Hamilton
Randolph Hawthorne
Stanley and Sone Heckman
Gary and Joanne Hunt
InterCommunication Inc.
Scott and Susan Jackson
Evan Jennings
Peter Kompaniez
Mark Kroll and Dr. Susan Kroll
Lewis Operating Corp.
Wanda Longsine
Paul and Monica Marx
Scott Mason and Karin Krogius
Duncan and Shirley Matteson, Sr.
Thomas and Laurie McManus
John and Julie Mitchell
Patrick and Barbara Moore
Robert Neal
Peter Nolden
George and Paula Norton
John and Trish O'Donnell
Tom and Dory O'Connor
David and RL Peters
Saul Pinto
Quintin Primo
Stephen Quinn and Pam Bellamy
Michael Rafferty
James and Janet Ray
James Reed
Earl and Barbara Rippee
Richard and Jane Robinson, Jr.
Steve and Trish Scarborough
Thomas and Jill Schriber
Mickey Segal
Maryam Shokrai
Robert and Lauren Silvernail
Don and Zoe Solsby
Robert and Betty Stine
Allan and Cindy Stokke
Style Interior Design, Inc.
James and Cassie Thomas
William and Leslie Thompson
Linwood Thompson
Thomas Toomey
Robert and Melissa Wagner
Richard and Dori Werner
Leonard and Carla Wood
Ronald and Janet Zuzack

\$250 AND MORE

Douglas Abbey
William and Annette Albert
Todd and Suzan Anderson
Robert and Tony Bader
Dennis and Nancy Bear
Laura Beuerlein
Bill Bloomfield, Jr.
Thomas and Debbie Britton, Jr.
Rebekah Brown
Richard Browne
Robert Burrill
James and Dori Caillouette
Daryl and Renee Carter
Michael Chadwick
Col. Robert and Maily Coates
Jeffrey and Paula Cole



Harbor Day School

Teens Make a Difference

Michael Bear, Andy Morrow and Blaine Bolus, three boys in Natalie's seventh grade class at Harbor Day School, were about to turn thirteen and decided to have a joint party to celebrate. Michael, Andy and Blaine have known Natalie since kindergarten and knew that Natalie has Cystinosis. Together they decided that instead of receiving birthday gifts, they would ask those invited to their party to make a contribution to the Cystinosis Research Foundation. They invited the entire seventh grade class to join them. Congratulations and thanks to the three young men and their friends who raised more than \$4,500 to help Nathalie and others with Cystinosis.



The story of the three young men who so generously included Natalie in their birthday celebration appeared on the front page of the Daily Pilot on November 30, 2003.

Two Long-term Studies Underway

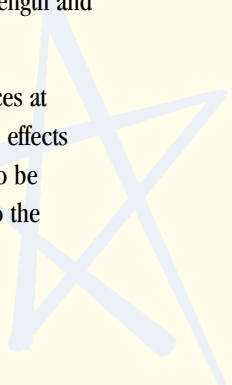
Cystinosis and Myopathy

The Cystinosis Research Foundation is pleased to announce the funding of a study by Doris A. Trauner, MD. Dr. Trauner is investigating the factors that contribute to myopathy, one of the most debilitating and potentially life-threatening complications of Cystinosis for young adults with the disease. Myopathy involves weakness and/or apathy of hand muscles, and swallowing or phonation difficulties. Nephropathic Cystinosis causes dysfunction or failure of multiple organ systems.

Dr. Trauner's study will focus on the progressive muscle weakness that affects the muscles of the mouth, face and throat, and of the hands and arms. Individuals with Cystinosis who develop myopathy have difficulty swallowing and chewing, and may choke on their food and develop aspiration pneumonia.

The study will involve ten adolescents and young adults with Cystinosis who have evidence of myopathic changes. They will be evaluated over the next two years to determine the metabolic causes of muscle weakness and to establish whether specific treatments will improve strength and prevent worsening of myopathy.

Dr. Trauner, is a Professor in the Department of Neurosciences at the University of California, San Diego, has been studying the effects of Cystinosis on the brain for many years. We are fortunate to be working with her and appreciate her effort and dedication to the Cystinosis community.



Friends Updates...



ZACHARY BEERS

Zachary Beers was featured on the video we presented at our 2003 fundraiser. Zachary is now in pre-school and enjoying every minute of it! He loves to sing, dance and play on the computer. He is also enrolled in speech and special physical education classes, and occupational therapy. He receives daily injections of growth hormone and happily, he is seeing results!

His father Rob just completed the Cysteamine Absorption Study as an adult volunteer. The study, funded by the Cystinosis Research Foundation, will hopefully result in finding a controlled-release medication eliminating the side-effects and frequency of the medicine.

SHANNON PAJU

Shannon Paju is the seventeen-year-old who spoke so eloquently on the video at last year's fundraiser. Unfortunately, Shannon has had a challenging year. In August, she was admitted to UCI Medical Center with chest pain and heart palpitations. Shannon was put on a ventilator and her prognosis was uncertain.

She was transplanted with a new kidney last year which created additional challenges. Shannon remained on the ventilator for four weeks. She left the hospital after a three-month stay but her return home was short-lived. She was rushed to the emergency room in November, and only recently returned home.

Shannon is gaining strength and has a fighting spirit. She is determined to graduate from high school this year with her friends.

Anything is Possible

- ❖ Many thanks to David Martin, a family friend who
- ❖ surprised us when he announced that he was going
- ❖ to run the Kona, Hawaii Marathon on behalf of Natalie.
- ❖ David successfully completed the marathon and did so
- ❖ with a picture of Natalie around his neck. In David's words:

When I first met Natalie I knew nothing about Cystinosis, and none of my friends had ever heard of it either. But the more I learned about Cystinosis and Natalie, the more I became aware of the fortitude and inner strength required by anyone living with this disease—and of the love and compassion of their families.

I asked myself, 'Why doesn't everyone know about Cystinosis? Is there a cure? What needs to be done to raise awareness of this disease? What can I do to help others ask these same questions?'

Anything is possible is a phrase one sees everywhere in Kona for the Ironman Triathlon in October and the Kona Marathon in June. For me, that phrase became symbolic of Natalie, Alex, Jeff and Nancy—and it was my inspiration for running the marathon. Running across lava fields in 100 degree heat for 26.2 miles for six hours is indeed daunting, but such a task pales in comparison to what a person with Cystinosis must endure 24 hours each day.

My marathon time was slower than I had anticipated, but for good reason; people along the course would yell out, 'Who is Natalie,' and "What is Cystinosis?" I took every chance to respond to their questions. When I crossed the finish line, I considered my time answering questions well spent—and the race, my best ever!

In October of this year, I expect to compete in the Ironman Triathlon. I will once again carry Natalie in my heart, but this time for the 2.4 mile swim, the 112 mile bike, and the 26.2 mile run. As they say, *anything is possible*.



Doughnut Days

At Harbor Day School



It is so sweet and nice to know that I am loved by children I don't even know. It made me feel so happy inside when I heard that one little boy was giving up his doughnut money for my disease. I had tears in my eyes and I almost cried. - Natalie

In December, a student in Mrs. Taylor's second grade class shared an article from The Daily Pilot. The article told about three boys who had performed "an act of kindness" to help their classmate, Natalie Stack. The boys were about to celebrate their birthdays at a combined party, but instead of receiving presents, the boys asked their guests to make donations to the Cystinosis Research Foundation. Mrs. Taylor explained to her class that the money would be given to doctors who are trying to develop a medicine that would help young people like Natalie, who have a serious disease called Cystinosis.

Mrs. Taylor, who was Natalie's second grade teacher, explained that Natalie has to take a horrible tasting medicine many times each day and night. The medicine is so powerful that it causes her to have stomach aches and headaches but Natalie never complained. She was a good student who was always excited about learning and playing with her friends.



After hearing about Natalie, the second graders wondered if they could help too. They wanted to donate money to the Cystinosis Research Foundation. During the following week, the students collected money which they put in an envelope with a red heart on it. Perhaps the most touching moment during the week occurred on "doughnut day" – a school event that takes place only once a month. One of the boys told Mrs. Taylor that he would "love to have a doughnut" that morning, but he wanted to give his dollar to help Natalie instead. It was a wonderfully kind deed by the young boy and a great example to others who can help.



One Sweet Donation

After hearing the story about Natalie at the fundraising event, troop leader Sarah Ciavarella shared *Natalie's Wish* with her Brownie Troop 1095 of Irvine, California. The girls decided to send part of their hard-earned Girl Scout cookie money to the Cystinosis Research Foundation. We were moved by their generous gift; however, the most special part of their gift was the beautiful hand-illustrated card.

The card was signed by all of the Brownies in the troop. Natalie was truly moved and humbled by the troop's outreaching of support and concern. Troop 1095's contribution will make a difference in the fight for a cure.

Donor List

\$35,000 AND MORE

Michael and Lynette Hayde
Geoffrey and Nancy Stack

\$10,000 AND MORE

CB Richard Ellis
Eastdil Realty Company, LLC
Paul Goldenberg
Ronald and Deborah B. Ratner
Philanthropic Fund
The Ryness Company

\$5,000 AND MORE

Roland Arnall
Robert and Christine Beers
Budge Collins
The Dialynas Family
Kris and Linda Elftmann
John and Marilyn French
Donald and Beth Anne Haarer
John and Merry Hagestad
George Marcus
Jose and Velyna Morales
Paul and Sue Ellen O'Connor
SARES-REGIS Group
Time Warner Connect
Ted and Sheila Weschler

Donor list continued on next page