

The courage of a remarkable young girl.
The passion of her family and friends.



THE POWER OF A WISH!

Natalie Stack with Kevin Sharp and Alex Stack



Nancy and Jeff Stack



Lynette and Michael Hayde



Bonnie, Shannon and Hillar Paju with Lyndsey Beeler



John and Merry Hagestad, Christine and Bill Thormahlen



Andy and Claire Mackay with Renee Carter and Elizabeth Anne Crawford

On Thursday, June 1, 2006 guests at *Natalie's Wish*, the fifth annual fundraising event for the Cystinosis Research Foundation, learned first hand just how powerful a wish can be.

In this case, it is the heartbreaking wish made by a then 12-year-old Natalie Stack, "To have my disease go away forever." And while Natalie's wish is far from reality, it has touched family members and friends alike and motivated them to help. The support of this ever-widening group is giving hope for the first time to a small number of children and young adults, and their families throughout the world who suffer from Cystinosis – the rare and deadly metabolic disorder that afflicts 500 children and young adults in the U.S., and only 2,000 worldwide.

More than 355 friends and supporters from around the country attended this year's event at the Balboa Bay Club in Newport Beach, and like past Natalie's Wish events it was an extraordinary evening for sharing and giving to a cause that many attendees are still learning about.

For most guests, including the eight Cystinosis families in attendance from throughout the country, it was an emotional evening they will likely never forget.

This year's event featured country music singer-songwriter Kevin Sharp, who is himself a survivor of a terrible disease – a bone cancer called Ewing's Sarcoma. The charismatic, award-winning performer is known for songs that convey his warmth, as well as his candor and honesty. His songs are easily recognizable as the work of a person with nothing to lose and everything to gain.

Kevin's *Make a Wish* track was especially poignant as it reminded each of us to follow our own dreams while being careful not to dash the hopes and dreams of others.

Although Kevin was the star performer, the evening's real star was the event's namesake, 15-year-old Natalie Stack. Natalie's mom and dad, Nancy and Jeff Stack, received surprise proclamation from Assemblyman Tom Umberg for their tireless work in founding the Cystinosis Research Foundation. Nancy also made a moving presentation, which is excerpted on page two.

Like each of the prior Natalie's Wish events this year was an awe-inspiring success. In fact, the event has become one of Orange County's most highly anticipated and most successful fundraisers, while never losing the family-like feeling and warm glow that are hallmarks of the event.

2006 attendees contributed more than \$1.3 million – smashing the previous Natalie's Wish record by \$500,000

As always, 100 percent of every dollar raised funds scientific research for new treatments and a cure for Cystinosis. In just five short years the Cystinosis Research Foundation has raised nearly \$4 million for research projects throughout the United States and Europe. Since January, the foundation has issued six new research grants totaling more than \$1.4 million with a second call for research proposals to be issued October 1, 2006.



EXCERPTS FROM NANCY STACK'S PRESENTATION ON JUNE 1, 2006

Thank you all for coming tonight – this is a night of celebration – of family and community. As many of you know, Cystinosis is a very rare disease an “orphan” disease, afflicting approximately 500 people, mostly children in North America, and less than 2,000 worldwide. Remarkably tonight, there are nine families here, including ours, with Cystinosis.

2006 APPROVED RESEARCH STUDIES

In the past, Cystinosis research studies were rare due to a lack of funding. Contributions from generous donors have changed the course of Cystinosis research. As a result of those contributions, the Cystinosis Research Foundation (CRF) has awarded 17 research grants, including six new grants listed below, totaling more than \$2,564,000 in funded and committed Cystinosis research over the last four years.

The studies have been evaluated and recommended for funding by the CRF's Scientific Review Board. Because of your continued support the CRF will announce another call for research grant proposals in October 2006.

A Study to Evaluate Enteric-Coated Cysteamine Therapy in Patients with Cystinosis

Ranjan Dohil, MD – UC San Diego
\$253,685: 1-year study

Characterization of Cystinosis Intracellular Trafficking

Corinne Antignac, MD, PhD
Hospital Necker, Paris, France
\$85,000: 1-year study

Treatment of Cystinosis Nephropathy Using Genetically Modified Adult Stem Cells in Murine Cystinosis Model

Daniel Salomon, MD and Stephanie Cherqui, MD
The Scripps Research Institute, La Jolla, California
\$709,170: 3-year study

Academic Functioning in Cystinosis: A Comprehensive Study of the Process of Achievement

Angela Ballantyne, PhD, and Amy Spilkin, PhD
University of California, San Diego
\$213,527: 2-year study

Pathogenesis of Interstitial Renal Damage Leading to Renal Failure in Cystinosis

E.N. Levtchenko, MD, PhD
University Medical Centre St. Radboud Nijmegen, The Netherlands
\$72,423: 1-year study

API-4000 Tandem Mass Spectrometer for Cystinosis Research

Bruce Barshop, MD, PhD and Jerry Schneider, MD
UC San Diego
\$118,400: 2-year lease and maintenance

The Cystinosis Research Foundation (CRF) will announce its second 2006 call for research proposals October 1, 2006. Research awards will be given for up to two years. Currently, the CRF has over \$1.2 million dollars in funds available.

The CRF is establishing the first post-doctoral Cystinosis research fellowship program in the United States to encourage young investigators to establish careers in Cystinosis research. Fellows will be funded for 2–3 years to a maximum of \$75,000/year. The number of awards and their value will depend on the number of outstanding proposal and the funds available at the time.

www.natalieswish.org

Fifteen years ago our daughter Natalie was diagnosed with Cystinosis – an incurable metabolic disease that slowly destroys every organ in the body including the liver, kidneys, eyes, muscles, thyroid and brain. There is a medicine that prolongs patients' lives, but there is no cure. Cystagon™, the powerful medication used to treat Cystinosis, causes horrific side effects and must be taken every 6 hours. The side effects and demanding 6-hour dosing schedule often result in poor compliance. Eye drops are available to stop the painful accumulation of cystine crystals on the corneas but they must be refrigerated and taken a minimum of 8 times a day. If the eye drops are stopped, the crystals reappear.

Cystinosis, like all orphan diseases, affects a small population. Government funding for rare disease research is minimal, and that funding must be allocated between the 6,000 rare diseases that collectively affect 25 million Americans. However, knowledge discovered by studying one disease may lead to advancements in other rare disease and more prevalent and well-known disorders. For instance, the drug to treat Cystinosis, is being studied as a possible therapeutic treatment for Huntington's, Parkinson's and other diseases.

Cystinosis slowly destroys every organ in the body including the liver, kidneys, eyes, muscles, thyroid and brain.

The Cystinosis Research Foundation's mission is two-fold; to find better treatments and a cure for Cystinosis. In 2003, the CRF issued a 2-year grant to Drs. Ranjan Dohil and Jerry Schneider to determine where Cystagon™, the current medication, is best absorbed in the body. The study was successfully completed last year. This year, Drs. Dohil and Schneider were awarded a grant to begin phase two of the study, and there is exciting news to report. The study tests an enterically coated form of Cystagon™. The coating hopefully acts to slow the release of Cystagon™. Dr. Dohil and Dr. Schneider report that the study looks promising and they are pleased with the initial results. If the data continues to unfold the way the doctors anticipate, we will be one step closer to changing the course of treatment for children and young adults with Cystinosis.



After a global call for research proposals in March of this year, and evaluation of each study by our Scientific Review Board, five proposals were recommended for funding. We have issued six new grants committing over **\$1.4 million dollars** to research. The studies are aimed at improving the quality of life for our children and also ultimately finding a cure for Cystinosis. As a result of your donations and support, we are now able to attract new doctors and investigators to study Cystinosis. Their enthusiasm, energy and talent allow us to continue to increase our knowledge of both the biology and the treatment of Cystinosis.

One of the new grants awarded was a 3-year grant to The Scripps Institute in La Jolla. Dr. Daniel Salomon and Dr. Stephanie Cherqui are the Principal Investigators and will be using adult cell stem cells as an alternative for the treatment of Cystinosis. After sending the award letter to The Scripps Institute, Dr. Cherqui emailed us this message:

“I'm so happy and honored by your trust. I will not disappoint you. I will do my best for this project and hopefully find a cure for Cystinosis. I am starting today.”

Each of you in this room has given us the gift of hope. Your support of this cause, of our family and the Cystinosis community has made an enormous difference in just four short years. The research studies, the progress being made, the new researchers studying Cystinosis, is the result of **the power of a wish**.

Our dear **Natalie**, whose courage and love of life, whose determination, bravery, infectious laughter, warm hugs and optimism reminds us of how precious life is and how quickly we must work to make her wish, “to have my disease go away forever” come true. There have been many tears and sleepless nights but our lives are so much richer because we are her parents. Because of Natalie, we have met all of you – she has connected us and we are so blessed to include all of you in our lives.

On behalf of all of the families with Cystinosis, thank you – this is a night of celebration, of hope, of making a difference. We could not do any of this without you – we are eternally grateful for your continued support and collective embrace. Thank you very much.

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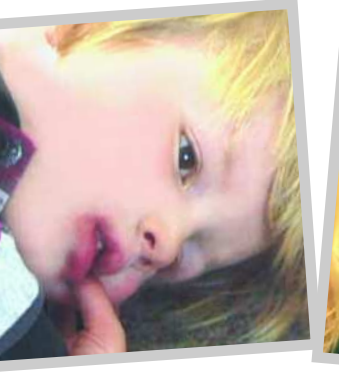
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The courage of a remarkable young girl.
The passion of her family and friends.



Natalie Stack, Christina Dialynas and Alexandra Stack



Standing second and third from left Kevin and Teresa Partington surrounded by family and friends

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Jeff and Nancy Stack receive a congressional proclamation from Assemblyman Tom Umberg for their efforts on behalf of the Cystinosis Community.