CRF STAR FACTS

CYSTINOSIS RESEARCH FOUNDATION

Natalie's Wish: to have my disease go away forever

April 2014

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Natalie's Wish Celebration

Thank you to all of the donors, cystinosis families and friends who attended the Natalie's Wish event on Saturday, April 5. We raised **$2.3 million** for new research aimed at finding new treatments and a cure. Natalie's wish is a wish heard around the world - our children inspire us and remind us that we must never give up until we find the cure.

More than 455 guests shared a night under the stars to honor the children and adults who are affected by cystinosis and celebrate the cystinosis research community for its commitment to our children. We hope you will join us next year on Saturday, April 18, 2015!

CRF Day of Hope Family Conference

Day of Hope
CYSTINOSIS RESEARCH FOUNDATION FAMILY CONFERENCE

The **Day of Hope Family Conference** was held April 3-5 and brought families together from across the globe to hear top cystinosis researchers share their progress on gene and stem cell therapies, novel eye treatments, kidney transplants and neurological issues related to cystinosis. Cystinosis families from the U.S. and Canada joined together to socialize and share stories during a weekend of hope and inspiration. The conference was sponsored by CRF, Raptor Pharmaceuticals and Sigma-Tau. Mark your calendars for next year's Day of Hope April 16-18, 2015.

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Jenna & Patrick's FOUNDATION OF HOPE

The 5th Annual Swing and Bling Event in honor of Jenna and Patrick's Foundation of Hope had a full field of 144 golfers Friday, February 21 at the Teal Bend Golf Course in Sacramento followed the next evening by a sold out dinner gala at the Citizen Hotel. The combined events raised more than $275,000 for cystinosis research. We are grateful to the Partington family and the Sacramento community for joining in the quest to find the cure.

24 Hours of Schweitzer, the annual event held March 21 in honor of Henry Sturgis, raised over $120,000 for cystinosis research. More than 110 skiers and snowboarders ages 5 to 73 from Idaho, Washington D.C., Iowa, California, Arkansas, Colorado and Washington state, took to the slopes for the round-the-clock relay. The ski event concluded with a dinner and awards party attended by 230 people. We appreciate the tireless efforts of the Sturgis Family, volunteers, board members and the community for their commitment to Hank and all those who are affected.

Music for Mary, a benefit concert held March 22 in honor of Mary Head, featured musical entertainment by the gifted artist Chris Anderson, an authentic Italian dinner and a special silent and live auction. The event raised more than $17,890 to help fund cystinosis research. Thank you to Melissa and JR Head along with their family and community of friends who work so diligently to help find a cure for cystinosis.

Saturday, May 17, 2014 - Lewiston, Idaho.
The Sixth Annual Wine, Stein and Dine Event will be held from 6:00 - 9:00 p.m. at the Rogers Toyota Scion Showroom to benefit Tina's Hope for a Cure. This community gathering, held in honor of Tina Flerchinger, has developed into the must attend culinary event of the year. Tickets are available online www.tinashopeforacure.org/events.html or contact Denice or Mark Flerchinger at (509) 243-4000.

Friday, June 6, 2014 - Hookstown, Pennsylvania
Third Annual Lots of Love for Landon Charity Golf Outing will be held at the Ponderosa Golf Course in honor of Landon Hartz. Registration deadline is May 30, and the fee is $100 per golfer which includes lunch, carts, and dinner. Hole sponsorships are available for $200. For more information contact Jason Whitfield at (412) 535-0022, jwhitfield@allenshariff.com

PUBLISHED STUDIES

The Proximal Tubule in Cystinosis: Fight or Flight? - Published in the Journal of the American Society of Nephrology by Robert Chevalier, MD, University of Virginia.

The Fate of Nephrons in Congenital and Heritable Renal Disorders - Published in the Journal of Pediatric and Neonatal Individualized Medicine, by Robert Chevalier, MD, University of Virginia.

CYSTINOSIS RESEARCH FOUNDATION

949-223-7610
cystinosisresearch.org

The mission of the Cystinosis Research Foundation is to support bench and clinical research that is focused on developing better treatments and ultimately a cure for cystinosis.

Cystinosis is an "orphan" disease affecting approximately 500 people, mostly children, in the U.S. and 2,000 worldwide.

Cystinosis is a metabolic disease that slowly and eventually destroys the organs in the body including the kidneys, liver, eyes, muscles and the brain. Although medication is available to control some of the symptoms, cystinosis remains incurable.