

Learn • Laugh • Share • Celebrate

DAY *of* HOPE

Cystinosis Research Foundation Family Conference



Thursday, April 19 – Saturday, April 21, 2012
Balboa Bay Club, Newport Beach, California

Learn, laugh, share and celebrate for three exciting days at the 2012 Cystinosis Research Foundation *Day of Hope Family Conference* and Natalie's Wish celebration at the beautiful Balboa Bay Club in Newport Beach, California.

- Top cystinosis researchers from around the world will share their progress on gene and stem cell therapies, novel eye research and neurological issues related to cystinosis.
- Raptor Pharmaceutical will provide an update on the RP103 delayed-release medication.
- Cystinosis families from around the world will meet, socialize and share their personal stories of life with cystinosis, as they participate in a weekend of hope and inspiration.

All conference sessions, conference meals and the Natalie's Wish event on Saturday night are free for cystinosis families.

**CYSTINOSIS**
RESEARCH FOUNDATION
cystinosisresearch.org





Here are the exciting events we have planned!

Thursday, April 19

6:00 – 8:30 pm Welcome Reception and Mexican Fiesta Dinner for the whole family overlooking beautiful Newport Beach Harbor.

Friday, April 20

8:00 – 4:30 pm Conference with breakfast and lunch served on the patio.

6:00 – 9:00 pm Families will gather on the beach, under the stars for an old-fashioned American cookout with music and entertainment.

Saturday, April 21

8:00 – 1:30 pm Conference with breakfast and lunch served on the patio.

2:00 – 5:30 pm Enjoy the afternoon on the beach, swimming in the pool or shopping at nearby Fashion Island.

6:00 – 10:00 pm Our Tenth Annual Natalie's Wish celebration, ***Wishes, Heroes and Miracles***, will celebrate the research community for its commitment to our children. We invite all families to attend as our honored guests. Professional sitters will be provided for conference sessions and on Saturday evening during the Natalie's Wish Event.

Hotel Information – Balboa Bay Club and Resort (www.balboabayclub.com)
1221 West Coast Highway, Newport Beach, CA 92660 ☆ Toll free (888) 445-7153

We have secured a special flat rate of \$175/night for cystinosis families. Visit the reservation site <https://roomres.balboabayclub.com/bbc/?requesttype=invBlockCode&code=CYSTINOSIS1204>

If you contact the hotel via phone be sure to mention CRF Group/Block code Cystinosis1204.



DAY *of* HOPE

Cystinosis Research Foundation Family Conference



Thursday, April 19 – Saturday, April 21, 2012
Balboa Bay Club, Newport Beach, California

Dear Families and Friends:

We are pleased to share information about our Third Annual *Day of Hope Cystinosis Family Conference*. It is a remarkable time for the cystinosis community – CRF-funded research has yielded the discovery of delayed-release cysteamine, which should soon receive FDA approval, and our researchers continue to make important discoveries about cystinosis gene and stem cell therapies.

We feel fortunate that we can again come together as families to support each other and recognize the brilliant researchers who have dedicated their lives to our children and celebrate the significant advances they have made in cystinosis research.

Our Tenth Annual Natalie's Wish celebration, ***Wishes, Heroes and Miracles***, on Saturday, April 21, will be a night filled with laughter and hope – and perhaps even a tear or two. Almost certainly, it will be our biggest and most heartwarming event ever.

Of course, attendance at the Natalie's Wish event is free for cystinosis family members, as are all sessions and meals during the conference.



We look forward to seeing you at the *Day of Hope Family Conference* as we unite as a community in our quest for a cure. We have worked to make the conference as relevant and engaging as possible and to ensure that every member of your family will enjoy their time at the beach at the spectacular Balboa Bay Club in Newport Beach.

We look forward to seeing you, and sharing and celebrating with you in April.

Nancy and Jeff



For more information, contact Nancy Stack at (949) 223-7610 or nstack@cystinosisresearch.org or Stacy Johnson at sjohnson@cystinosisresearch.org.

Photos from the 2011 Day of Hope Family Conference



Dr. Paul Grimm presenting to participants



Adult panel discussion



Children connecting through laughter and play



Researchers and families sharing time together



Enjoying the fun and games



Socializing while having lunch on the patio



CYSTINOSIS RESEARCH FOUNDATION
NATALIE'S WISH

For more information, contact Nancy Stack at
(949) 223-7610 or nstack@cystinosisresearch.org or
Stacy Johnson at sjohnson@cystinosisresearch.org.