



Day of Hope

CYSTINOSIS RESEARCH FOUNDATION FAMILY CONFERENCE

**Thursday, April 3 through
Saturday, April 5, 2014**

Balboa Bay Resort, Newport Beach, California

The 2014 *Day of Hope* Family Conference will take place over three days and culminate on Saturday night at the Twelfth Annual Natalie's Wish Celebration.

The conference will focus on the progress CRF-funded researchers have made over the past several years. Sessions will include:

- Research news about stem and gene therapy
- Novel eye treatment research progress
- Research updates related to kidney disease
- Update on the effects of muscle wasting
- Report on the Cure Cystinosis International Registry (CCIR)



Learn • Laugh • Share • Celebrate



Here are the exciting events we have planned!

THURSDAY, APRIL 3

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

FRIDAY, APRIL 4

8:00 a.m. – 5:00 p.m. Conference sessions with breakfast and lunch served on the patio.

6:30 p.m. – 9:00 p.m. Families will gather on the beach, under the stars for an Italian Feast with music and entertainment.

SATURDAY, APRIL 5

8:00 a.m. – 1:00 p.m. Conference sessions with breakfast and lunch served on the patio.

1:00 p.m. – 6:00 p.m. Enjoy the afternoon on the beach, swimming in the pool or shopping at nearby Fashion Island.

6:00 p.m. – 10:00 p.m. Our 2014 Natalie's Wish event, *Night of A Thousand Stars*, will celebrate cystinosis families and the research community for its commitment to our children. This exciting evening will feature a special performance by *The Tenors*, the exhilarating Canadian quartet who have performed for presidents, prime ministers and royalty. 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.

10:00 p.m. – 12:00 a.m. You are welcome to join us at the after-party to celebrate!



please join us

Hotel Information – Balboa Bay Resort (www.balboabayresort.com)

1221 West Coast Highway, Newport Beach, CA 92663 ★ Toll free (888) 445-7153

We have secured a special flat rate of \$185/night for cystinosis families and \$199/night plus tax and gratuity for other guests. To make your reservations call (888) 445-7153, be sure to mention "cystinosis family" to receive the discounted family rate.

Dear families and friends



We are pleased to share the latest information about our Fifth Annual Day of Hope Cystinosis Family Conference. We feel fortunate that we can once again come together as families to support each other and celebrate all we have collectively accomplished.

It is a time of great excitement for the cystinosis community. Researchers from around the world continue to make remarkable progress in our journey towards the cure. To date, they have published 45 articles resulting from CRF-funded research in major scientific journals.

The conference will focus on the work of some of our most committed CRF researchers including Dr. Stéphanie Cherqui, Dr. Ranjan Dohil, Dr. Paul Grimm, Dr. Sergio Catz, Dr. Robert Mak, Dr. Jennifer Simpson, and Dr. Ghanashyam Acharya, who will all be attending the conference.

**A FAMILY ASSISTANCE
FUND WILL BE AVAILABLE.
CONTACT NANCY STACK
FOR MORE INFORMATION.**

Night of A Thousand Stars, our 2014 Annual Natalie's Wish celebration, on Saturday, April 5, will be a magical night filled with inspiration and hope.

This exciting evening will feature a special performance by *The Tenors*, the exhilarating Canadian quartet who have performed for presidents, prime ministers and royalty.

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 in April as we unite as a community in our quest for a cure. Past attendees continue to share wonderful stories about their experiences at the conferences. We have worked hard to ensure that this year's conference is equally engaging and rewarding, and that every member of your family will enjoy their time at the spectacular Balboa Bay Resort in Newport Beach.

We look forward to seeing you, learning from you, and sharing and celebrating with you in the near future.

Nancy and Jeff Stack

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



At our 2014 Day of Hope Family Conference, there will be plenty of time to
Learn • Laugh • Share • Celebrate



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we look forward to seeing you at our 2014 conference.