



**together**

we're turning hoping into happening



day of

**hope20**



day of  
**hope20**

Cystinosis Research Foundation

**JOIN US**

For The 2020 Day of Hope Family Conference

Cystinosis families around the world are united in the quest for a cure. Together we have funded 187 multi-year research studies which have led to new discoveries about cystinosis, a new FDA approved treatment and recently, FDA approval for a stem cell and gene therapy clinical trial that we hope will stop the progression of cystinosis and be a cure for cystinosis.

We will celebrate our cystinosis community at the Day of Hope family conference, and we will renew our efforts to work together to support research that will improve the lives of our adults and children with cystinosis.

**Thursday, April 16, 2020 – Saturday, April 18, 2020**

# CRF Day of Hope Family Conference

REGISTER TODAY

[crfevents.smapply.org/prog/Day\\_of\\_Hope\\_2020](http://crfevents.smapply.org/prog/Day_of_Hope_2020)



The conference will include important sessions led by CRF-funded researchers and clinicians.

## Confirmed speakers include:

### Stéphanie Cherqui, PhD

University of California, San Diego  
*San Diego, CA*

### Morgan Fedorchak, PhD

University of Pittsburgh School of Medicine  
*Pittsburgh, PA*

### Benjamin “Beno” Freedman, PhD

University of Washington,  
*Seattle, WA*

### Paul Grimm, MD

Stanford University School of Medicine  
*Palo Alto, CA*

### Larry Greenbaum, MD, PhD, FAAP

Emory School of Medicine  
*Atlanta, GA*

### Stephen Jenkins, MD

University of Utah School of Medicine  
*Salt Lake City, UT*



## Exciting Events We Have Planned

### Thursday, April 16

- Conference Begins
- Family Introductions
- Welcome Reception & Dinner

### Friday, April 17

- Conference Sessions
- Family Lunch
- Dinner Under the Stars at *Newport Dunes*



## Book Your Hotel Reservations - CRF Day of Hope

To book your room visit [fashionislandhotel.com](http://fashionislandhotel.com) Click “Book Now” and enter dates, then click “Add Code” and enter **CYST04152020**

We have secured a special flat rate of **\$205/night** for cystinosis families and **\$225/night** plus tax and fees for other guests. When booking your hotel room online, the \$205 rate will not show on your confirmation form, but will be confirmed upon check-in. The conference family special rate of \$205 is for four nights only.

Attendance at the Natalie’s Wish event is free for all Day of Hope conference attendees, as are all of the sessions, childcare and meals during the conference.

### Saturday, April 18

- Conference Sessions
- Family Lunch
- Free Social Time

### Saturday, Evening

- Please Join Us at Natalie’s Wish Celebration!



690 Newport Center Dr,  
Newport Beach, CA 92660  
[www.fashionislandhotel.com](http://www.fashionislandhotel.com)



[cystinosisresearch.org](http://cystinosisresearch.org)

The Cystinosis Research Foundation is a non-profit, tax-exempt entity pursuant to Section 501(c)3. • Federal Tax ID #32-0067668. • The Day of Hope invitation package was completely underwritten by friends of the Cystinosis Research Foundation.

*D*ear Family and Friends,

The generosity of our community never ceases to amaze us. Driven by our foundation's relentless quest for a cure, cystinosis families from all over the world have come together to fund 187 multi-year research studies which have led to a new FDA approved drug, a potential treatment for corneal cystinosis, exciting new scientific discoveries about cystinosis and the start of an FDA approved stem cell and gene therapy clinical trial for cystinosis. We will celebrate these blessings at the Day of Hope family conference and bring our collective passion together as we seek an even brighter future.

This is a time of great excitement and anticipation for the cystinosis community. Researchers from around the world continue to make remarkable progress; their success and new discoveries have brought us closer to finding a cure for cystinosis. CRF's dedication to funding new research grants twice a year has created a dynamic cycle of research and ensures that donations are always at work. It comforts all of us to know that because we fund researchers in 12 countries there is a researcher or scientist working diligently on cystinosis every minute of the day!

To date, CRF has raised over \$54 million making us the largest private fund provider of cystinosis research in the world! We are blazing this path together, united as a community and focused on finding better treatments and a cure. Our conference sessions will concentrate on the key areas of cystinosis research — the kidneys, the eyes, myopathy and muscle wasting, bone issues and stem cell

and gene therapy. This year we will receive an update on the stem cell and gene therapy clinical trial and we will learn about other potential clinical trials that are on the horizon. We will have special sessions for newly diagnosed families, tweens and teens, and adults with cystinosis.

Some of the outstanding researchers and clinicians who will attend the Day of Hope include Stéphanie Cherqui, PhD, Morgan Fedorchak, PhD, Benjamin "Beno" Freedman, PhD, Larry Greenbaum, MD, PhD, Paul Grimm, MD and Stephen Jenkins, MD.

Our 2020 Annual Natalie's Wish Celebration on Saturday night, April 18, will be a night filled with hope, inspiration and gratitude. We will be entertained once again by Matt Mauser and his Sinatra Big Band.

We look forward to seeing you in April at the spectacular Fashion Island Hotel in Newport Beach as we unite in our quest for the cure and we celebrate our adults and children with cystinosis who inspire us and teach us so much about life. We know that you will find the conference engaging and rewarding. United as a community, we are changing the course of cystinosis. Together, we shine bright!

Warm Regards,

*Nancy & Jeff*

Nancy & Jeff Stack

