

General Information

CFRI's National Cystic Fibrosis Family Education Conference

Our annual conference brings together national experts in the field of CF to provide the latest updates in research and care, while offering opportunities to meet other members of our diverse CF community.

Registration Fees: Full Conference

Early Bird Registration (on or before 6/28/17) - \$185 per person.

Regular Registration (on or after 6/29/17) - \$215 per person.

Includes conference meals, reference materials, all presentations, receptions, and support groups. Continuing Education Units may be available. Go to www.cfri.org for information.

Registration Fees: CFRI-Funded Research Track (July 29 - 30)

Two-Day Registration - \$125 includes Saturday and Sunday lunch

One-Day Registration - \$75 includes lunch

Attendance is limited to Research Track presentations and two designated general sessions. Continuing Education Units may be available. Go to www.cfri.org for information.

Pullman Hotel Reservations - \$119 Discount Rate

Reservations must be made prior to 5:00 pm on Wednesday July 14, 2017 to guarantee this rate. Please make your reservations online at www.cfri.org or call Pullman at 650.598.9000. You must request a CFRI-rate Superior Room (double or king) to receive the \$119 discount rate (plus taxes and fees). A first-night room deposit or guarantee with a major credit card must accompany all reservation requests. Cancellations must be made 72 hours prior to your arrival date, or you will be billed for one night room and tax. A complimentary shuttle service is available every hour between 6:00 am and 11:00 pm to and from SF Airport (SFO) and Pullman.

Medical Safety for All is Our Priority

Anyone who is sick may not attend. All attendees must use proper hygiene practices. Attendees with CF must complete a sputum culture at a CFF-accredited CF treatment center laboratory after June 16, 2017. The results, as well as a completed CFRI Medical Release Form and Cross-Infection Liability Release Form, must be delivered to CFRI's office by July 25, 2017. Please download forms at www.cfri.org. In line with updated CF best practices for cross-infection prevention, those with CF must maintain a six-foot space between others with CF.

For more information, visit www.cfri.org or call 1.855.cfri.now.

Supported By: **Genentech, Vertex Pharmaceuticals, Gilead Sciences, Inc., Chiesi USA, AbbVie, the Boomer Esiason Foundation, and Novartis Pharmaceuticals**



Soaring to New Heights
Early Bird Discount! June 28, 2017 deadline!
www.cfri.org

30th National Cystic Fibrosis Family Education Conference



Research for Living ~ Partners for Life



Early Bird Discount! June 28, 2017 deadline!

Soaring to New Heights

July 28 - July 30, 2017

Pullman San Francisco Bay
Redwood City, California

Registration Form

All conference attendees must be at least 18 years old.

Please submit one form per person (copy if necessary) or register at www.cfri.org.

Name _____

Address _____

City, State, Zip Code _____

Phone _____ E-mail _____

What is your relationship to CF?

Adult with CF Parent Grandparent Other Relative Spouse/Partner

Friend Speaker Healthcare Provider

Sponsor/Exhibitor (Company): _____

Is this your first CFRI Conference? Yes No

Are you or your loved one newly diagnosed within the last 12 months? Yes No

How did you hear about the conference? _____

How many nights are you staying at Pullman SF Bay? _____

Make your reservations at www.cfri.org or call Pullman at 650.598.9000 (M - F 7:00 am - 7:00 pm PST, or Sat. 8:00 am - 4:30 pm PST). Ask for CFRI's discount group room rate of \$119 (Superior Room) by 5:00 pm on July 14.

What is your preference for meals? Vegetarian Non-Vegetarian

Please help CFRI avoid unnecessary meal charges by checking only the meals that you will be present for: Friday Reception/Dinner Saturday Breakfast Saturday Lunch Saturday Eve. Reception Saturday Dinner Sunday Breakfast Sunday Lunch

If you wish to attend an activity or support group, please check one:

Each group needs at least 5 people. We will notify you if a group cannot be formed.

Adults with CF Spouses/Partners/Siblings of Adults with CF

Parents/Relatives of those with CF who are:

___ Newly Diagnosed (0-3 yrs) ___ Children (4-11) ___ Adolescents (12-17) ___ Adults (18+)

Healthcare Providers Those who are Grieving SoulCollage® (art group)

Early Bird Registration (received by CFRI on or before 6/28/17) - \$185 per person.

Regular Registration (received 6/29/17 or after) - \$215 per person.

Research Track: Two-Day Registration - \$125 One-Day Registration - \$75

Payment Method: Check Credit Card Amount Enclosed: \$ _____

Credit Card # _____ Exp. Date _____

Name on Credit Card _____

Card Holder Signature _____

Register at www.cfri.org or mail this form and payment to:

Cystic Fibrosis Research, Inc. (CFRI)

1731 Embarcadero Road, Suite 210, Palo Alto, California 94303 USA

Toll Free 855.cfri.now (855.237.4669) Fax: 650.561.4074

If you have questions about any medical issues or conditions, consult your primary healthcare provider. Do not rely upon information presented at the conference for medical diagnosis or treatment.

Conference Schedule

Friday, July 28, 2017

- 4:00 pm Registration
- 4:30 pm Conference Orientation
- 5:30 pm Reception / Light Dinner, Networking, Entertainment
- 7:00 pm **Welcome & Opening Remarks** — Sue Landgraf, CFRI Executive Director
- 7:15 pm **Lessons from a CF Cornerman** — Ray Poole, MBA
- 8:00 pm **What Gets in the Way? Understanding & Supporting Treatment Adherence in CF** — Kristin Riekert, PhD
- 9:00 pm Soaring to New Heights Reception - Sponsored by AbbVie

Saturday, July 29, 2017

- 7:00 am Registration, Breakfast Buffet Opens
- 8:45 am **Welcome & Opening Remarks** — Sue Landgraf, CFRI Executive Director
- 9:00 am **CF Research Update 2017: Crossing the Bridge to a Cure** — John P. Clancy, MD
- 10:10 pm Stretch / Break
- 10:20 am **CF Beyond the Lungs: The Role of Physical Therapy** — Karen von Berg, DPT
or
CFRI Research Track Opens: Overview and Welcome — Julie Desch, MD
- 10:30 am **Development of a Novel Biomarker of CFTR Function** — Andrey Malkovskiy, PhD*
- 11:20 am **What to Expect When You're Expectorating** — Lucas Hoffman, MD, PhD
or
Measuring Beta-Adrenergic Stimulated Sweat Rate by a Capacitive Sensor — Danieli Salinas, MD, Research Track
- 1:40 pm **Beyond CF: Adult Health Issues** — Cathy Chacon, RN
or
Cystic Fibrosis & Respiratory Therapy — Carol Power, RRT
or
Assessing Secretory and Absorptive Phenotypes of Epithelial Cells in Conductive Airways — Guillermo Flores-Delgado, PhD, Research Track
- 2:45 pm **Thirty Years of CF Research Breakthroughs** — Paul Quinton, PhD
- 4:00 pm Support Groups / Workshops
- 6:00 pm All in for CF Reception — Hosted by Vertex Pharmaceuticals
- 7:00 pm Awards Banquet Dinner
- 9:00 pm Dance Party — Hosted by Rock CF Foundation

Sunday, July 30, 2017

- 7:00 am Registration, Breakfast Buffet Opens
- 9:00 am **Mind Body Therapies in Cystic Fibrosis Care** — John Mark, MD
or
Small Molecule Screening Approaches to Validate CF-Relevant Drug Targets — Peter Haggie, PhD, Research Track
- 10:00 am **Ask the Experts Panel** — Soaring to New Heights Conference Presenters
or
Improving Drug Delivery in Cystic Fibrosis Using Exercise — Noud van Helmond, MD*
- 11:00 am **Therapeutic Potential of RTD-1 for Treatment of Airway Infection/Inflammation in CF** — Paul Beringer, PharmD, Research Track
- 11:30 am Close of Auction/Pullman Room Check Out
- 12:15 pm Lunch and Presentation: **Belonging and Identity - Growing Up with CF** — Isa Stenzel Byrnes, LCSW, MPH
- 1:15 pm **Closing Remarks** — Sue Landgraf, CFRI Executive Director

Times and presenters may change. For updates, visit www.cfri.org.

*Research Track

MEDICAL SAFETY FOR ALL IS OUR PRIORITY

Individuals who have had confirmed or cultured for...

- Burkholderia cepacia (B. cepacia) complex at any time;
- Methicillin-resistant Staphylococcus aureus (MRSA) within the past 12 months;
- non-tuberculous mycobacterium (NTM) twice within 12 months; or
- bacterium resistant to all antibiotics (pan resistant)

...may NOT attend the conference because of the cross-infection risks to others with cystic fibrosis.

Please read CFRI's Infection Control Policy and download forms at www.cfri.org.

Conference Presenters



Isa Stenzel Byrnes, LCSW, MPH
Mission Hospice - Redwood City, CA



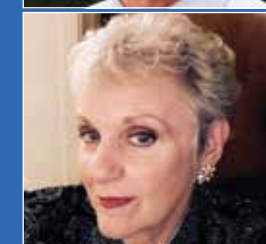
Cathy Chacon, RN
National Jewish Health - Denver, CO



John P. Clancy, MD
Cincinnati Children's Hospital Medical Center
Cincinnati, OH



Lucas Hoffman, MD, PhD
UW / Seattle Children's Hospital - Seattle, WA



Kristin Riekert, PhD
Johns Hopkins University School of Medicine
Baltimore, MD



Ray Poole, MBA
Author - Fort Thomas, KY



John Mark, MD
LPCH / Stanford University School of Medicine
Palo Alto, CA



Paul Quinton, PhD
UC San Diego - La Jolla, CA



Carol Power, RRT
Stanford Health Care - Palo Alto, CA

Research Track Presenters



Karen von Berg, DPT
Johns Hopkins University School of Medicine
Baltimore, MD



Paul Beringer, PharmD
USC - Los Angeles, CA



Guillermo Flores-Delgado, PhD
UC San Diego - La Jolla, CA



Peter Haggie, PhD
UC San Francisco - San Francisco, CA

Noud van Helmond, MD
Mayo Clinic - Rochester, MN

Andrey Malkovskiy
Stanford University School of Medicine
Palo Alto, CA

Danieli B. Salinas, MD
University of Southern CA / CHLA
Los Angeles, CA