



# General Information

## CFRI's National Family CF Education Conference

Every year, CFRI's National Family CF Education Conference supports parents, teens and adults with CF, and healthcare providers. Doctors, researchers and therapists bring their expertise from across the country and abroad to share valuable information.

## Registration Fees

**Early Bird Registration (on or before 7/1/11) - \$175 per person.**

**Regular Registration Fee (after 7/1/11) - \$195 per person.**

The registration fee includes five meals, reception, beverage break, lectures, reference materials and admission to all workshops and support groups. Full and partial scholarships are available but limited. For more information, visit [www.CFRI.org](http://www.CFRI.org) or call 650.404.9975.

## Continuing Education Units (CEUs)

CEUs are available for nurse practitioners, nurses, coordinators, social workers, dietitians, respiratory therapists and other healthcare providers. To apply: 1) Mail conference registration form and fee to CFRI; and 2) Mail CEU form and tuition fee (1.0 unit \$60; 1.5 units \$90) to San Jose State University. For more information, visit [www.CFRI.org](http://www.CFRI.org) or call 650.404.9975.

## Sofitel Hotel Reservations - \$97 Discount Rate

Sofitel is offering CFRI guests a Discount Group Room Rate of \$97 per night. You can make your reservations online at [www.CFRI.org](http://www.CFRI.org) or call Sofitel at 650.598.9000. Request a *Superior Room* (double or king) to receive CFRI's Discount Group Room Rate. Reservations must be made prior to 5:00 PM on July 7, 2011 to guarantee this rate. This rate is also subject to a 10% room tax and \$1.50 tourism assessment at the time of check in. All extra charges are the responsibility of the occupant (i.e., outside phone charges, room service, etc.). A first night room deposit must accompany all reservation requests or be guaranteed with a major credit card. All cancellations must be made 72 hours prior to your arrival date or you will be billed for one night room and tax.

Check-in time is 3:00 PM; check-out is 12:00 noon. Guests arriving before 3:00 PM. will be accommodated as rooms become available. The Concierge can arrange to check baggage for those arriving early when rooms are not yet available and for guests attending afternoon functions on their day of departure. Complimentary shuttle service is available every hour between 6:00 AM and 11:00 PM to and from SFO Airport and Sofitel (223 Twin Dolphin Dr., Redwood City, CA, Ph: 650.598.9000).

## Medical Safety

All attendees with cystic fibrosis must complete a sputum culture and must submit a physician's Medical Release Form and Cross-Infection Liability Release Form to CFRI's office before attending the conference. Please download these forms at [www.CFRI.org](http://www.CFRI.org) or call 650.404.9975. **If you have cystic fibrosis, you must complete a sputum culture after June 16, 2011 and your forms must be on file at CFRI's office by July 28, 2011.** Individuals who have ever had a confirmed positive sputum culture for *Burkholderia cepacia* (*B. cepacia*) or who have cultured *Methicillin-resistant Staphylococcus aureus* (MRSA) within the past two years or who are currently culturing a bacterium resistant to all antibiotics (pan resistant) may NOT attend the conference because of the cross-infection risks to others with CF.

**CFRI**<sup>TM</sup> Cystic Fibrosis Research, Inc.  
2672 Bayshore Parkway, Suite 520  
Mountain View, CA 94043 USA  
650.404.9975 Fax: 650.404.9981  
CFRI@cfri.org [www.CFRI.org](http://www.CFRI.org)



Cystic Fibrosis Research, Inc.

# 24<sup>th</sup> National Family CF Education Conference

## *Cystic Fibrosis in the Spotlight: Taking A Leading Role*

July 29 - July 31, 2011  
Sofitel San Francisco Bay  
Redwood City, CA

Early Bird Registration  
Register at [www.CFRI.org](http://www.CFRI.org)  
or mail Registration Form!  
(See inside.)

# Registration Form

All attendees with cystic fibrosis must complete a sputum culture and must submit a physician's Medical Release Form and Cross-Infection Liability Release Form to CFRI's office before attending the conference. Please download forms at [www.CFRI.org](http://www.CFRI.org) or call 650.404.9975. **If you have cystic fibrosis, you must complete a sputum culture after June 16, 2011 and your forms must be on file at CFRI's office by July 28, 2011.**

Please submit one form per person (copy if necessary) or register at [www.CFRI.org](http://www.CFRI.org).

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, ZIP Code \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

## What is your relationship to CF?

- Parent  Grandparent  Other Relative  Spouse  Adult with CF  
 Teen with CF  Friend  Speaker  Panelist  Healthcare Provider  
 Sponsor/Exhibitor (Please specify): \_\_\_\_\_

Is this your first CFRI Conference?  Yes  No

Are you applying for a scholarship to attend the conference?  Yes  No

If so, go to [www.CFRI.org](http://www.CFRI.org) to apply online or call 650.404.9975 for an application.

Are you applying for Continuing Education Units (CEUs)?  Yes  No

How many nights are you staying at Sofitel Hotel? \_\_\_\_\_

Make your reservations at [www.CFRI.org](http://www.CFRI.org) or call Sofitel at 650.598.9000.

Remember to ask for CFRI's Discount Group Room Rate of \$97 (*Superior Room*).

What is your preference for meals?  Vegetarian  Non-Vegetarian

CFRI subsidizes meals so please only check meals where you will be present:

- Friday Reception  Saturday Breakfast  Saturday Lunch  Saturday Dinner  
 Sunday Breakfast  Sunday Lunch

If you wish to attend a support group, please check one:

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

- Parents/Relatives of Newly Diagnosed Infants (0-2 years old)  
 Parents/Relatives of Pre-Schoolers (3-5 years old)  
 Parents/Relatives of School-Aged Children  Parents/Relatives of Adolescents  
 Parents/Relatives of Adults with CF  Dads  Siblings of those with CF  
 Adults with CF  Spouses or Significant Others of Adults with CF  
 Those who are Grieving  Healthcare Providers

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

Credit Card # \_\_\_\_\_ Exp. Date \_\_\_\_\_

Name on Credit Card \_\_\_\_\_

Card Holder Signature \_\_\_\_\_

Register at [www.CFRI.org](http://www.CFRI.org)  
or mail this form and payment to:

Cystic Fibrosis Research, Inc. (CFRI)

2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043 USA

650.404.9975 Fax: 650.404.9981

# CFRI Conference Schedule

## Friday, July 29, 2011

- 4:00 PM Registration  
**The Limelight Lounge** and Silent Auction Opens
- 4:30 PM **Conference Orientation:**  
**Get the Most Out of Your Conference Experience**
- 5:30 PM Reception and Networking, Musical Entertainment
- 7:00 PM Welcome, Introductions and Cross-Infection Control Discussion  
Carroll Jenkins, Executive Director, CFRI
- 7:15 PM Parallel Tracks:  
▶ **Growing Up Jordy Pordy Award-Winning Performance**  
Jordan Herskowitz, Artistic Director, New York, NY  
▶ **Cystic Fibrosis 101, Q & A**  
Isa Stenzel Byrnes, M.S.W., Kasey Pearson, N.P.,  
David Blackney, R.T., Marilyn Tsang, G.C.
- 9:00 PM **The Limelight Lounge**

## Saturday, July 30, 2011

- 7:00 AM Registration, Breakfast Buffet
- 8:40 AM Welcome and Cross-Infection Control Discussion  
Bill Hult, President, CFRI Board of Directors
- 9:05 AM **CF Gastrointestinal Problems – What You Can Do**  
Ronald J. Sokol, M.D., University of Colorado School of Medicine,  
Aurora, CO
- 10:00 AM Parallel Tracks:  
▶ **Genetic and Environmental Factors in CF Health**  
J. Michael Collaco, M.D., Johns Hopkins Hospital, Baltimore, MD  
▶ **Elizabeth Nash Memorial CF Research Presentations**
- 10:55 AM **Tips and Tools to Enhance Airway Clearance**  
Maggie McIlwaine, M.C.S.P., British Columbia Children's Hospital,  
Vancouver, B.C., Canada
- 12:15 PM Lunch
- 1:15 PM Parallel Tracks:  
▶ **CF Adult Panel Discussion: From Resistance to Acceptance**  
Tiffany Christensen, Kristina Benson, David Cartnel,  
Eric Marten, Scott Peterson, Joey Yerves  
▶ **New Horizons CF Research Presentations**  
Daniel Hassett, Ph.D., University of Cincinnati, Cincinnati, OH  
Dieter Gruenert, Ph.D., University of California San Francisco,  
San Francisco, CA
- 3:15 PM Parallel Tracks:  
▶ **Support Groups**  
▶ **CF Research Presentations**  
Paul Quinton, Ph.D., University of California San Diego, La Jolla, CA  
Weidong Kong, Ph.D., University of California San Francisco,  
San Francisco, CA
- 6:30 PM Wine Reception
- 7:00 PM Dinner Banquet, Awards, Raffle Drawing
- 9:00 PM ▶ **Memorial Tributes**  
▶ **The Limelight Lounge**

## Sunday, July 31, 2011

- 7:30 AM Registration  
Breakfast Buffet
- 8:50 AM Welcome and Cross-Infection Control Discussion
- 9:05 AM **Understanding CF Infections and Identifying Treatment Strategies**  
Pradeep Singh, M.D., University of Washington, Seattle, WA
- 10:00 AM **An Overview of Sleep-Related Problems in Cystic Fibrosis**  
Nanci Yuan, M.D., Stanford University School of Medicine, Palo Alto, CA
- 10:55 AM **What You Need to Know About Cystic Fibrosis Related Diabetes (CFRD)**  
Richard Cohen, M.D., Kaiser Permanente, Portland, OR
- 11:45 PM Lunch, Silent Auction Closes
- 1:15 PM **Your Health Matters: Being An Effective Advocate**  
Tiffany Christensen, Patient Advocate, Coordinator and Author,  
Raleigh-Durham, NC
- 2:00 PM **Ask the Medical Experts Panel Discussion**  
Richard Cohen, M.D.  
J. Michael Collaco, M.D.  
Maggie McIlwaine, M.C.S.P.  
Pradeep Singh, M.D.  
Nanci Yuan, M.D.
- 4:00 PM Closing Remarks

## Medical Safety is Our Priority!

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All cultures must be taken at a CFF Accredited CF treatment center laboratory. If you are hospitalized after submitting your culture, you must arrange for another culture report to be done at discharge. If you have had a lung transplant, you must submit a Medical Release to CFRI. This must be approved by your physician and may be based on your most recent bronchoscopy, if you cannot produce a sputum culture.

Bacteria can be transmitted through casual contact or close proximity to infected individuals and may cause serious respiratory illness. Some patients with *Burkholderia cepacia* may experience a rapid decline in lung function, possibly leading to death. For this reason, CFRI is very strict about this policy. Individuals with CF who arrive at the conference without a signed Medical Release will be asked to leave. CFRI cannot guarantee a conference free of risk for cross-infection of viruses or bacteria. We urge you to discuss cross-infection with your physician and decide for yourself if you should attend the conference.