



2011 Annual Report

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What is Cystic Fibrosis?

Cystic fibrosis (CF) is an inherited disease that affects the respiratory, digestive and reproductive systems. A genetic mutation results in thick mucus that blocks small passageways in the lungs, intestines and other organs. The mucus also traps bacteria, resulting in serious infections. CF is not contagious.

With the implementation of newborn screening programs, most people are diagnosed at a very young age. Early treatment, which may include nutritional and respiratory therapies, medications and exercise, has a significant impact on the quality of life for those with CF. As of today, there is no cure.

When was CF identified?

CF was first identified in 1938. At that time, children with CF rarely survived childhood. Today, thanks to innovative research leading to new medications, treatments and lung transplantation, the median life expectancy of someone with CF is now thirty-seven years.

Who do we serve?

Cystic Fibrosis Research, Inc. (CFRI) was founded in 1975. We serve everyone living with or affected by CF, including individuals with CF, their parents and caregivers, health care providers, researchers and medical professionals.

Hundreds of volunteers assist CFRI to accomplish its mission. CFRI is a 501(c)(3) nonprofit organization.

What Programs and Services are provided?

In 2011, CFRI funded eight projects through the Elizabeth Nash Memorial Fellowship, and the New Horizons Research Campaign, that investigate the complex science of this disease.

CFRI also provided resources to support the CF community, and conducted vital outreach and advocacy. These include the National CF Family Education Conference, Teen and Adult Retreat, the CF Discovery Series™, educational publications, and our newsletters.



Photo on left:  
CFRI 2011 Teen and Adult Retreat  
Vallombrosa, Menlo Park, CA  
Photo by Craig Burleigh

Photo on front cover:  
Miguel Gutierrez, Gina Serrato,  
and their 2-year-old daughter with CF,  
Gianna Gutierrez-Serrato  
Photo by Christian Urricariet



**CFRI**™ Cystic Fibrosis Research, Inc.  
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CFRI funds research,  
provides educational and personal support,  
and spreads awareness of cystic fibrosis,  
a life-threatening genetic disease.

# Connecting CF Resources with Community Needs

## EDUCATION

**CFRI live!**  
REGISTER EARLY to view presentation LIVE:  
**CF Discovery Series™**  
**CF Airway Clearance -- on the GO!**  
Presented by  
Kristin Shelton, R.C.P., R.R.T.,  
CF Respiratory Therapy Coordinator,  
Lucile Packard Children's Hospital at Stanford

CFRI produces a series of dynamic interactive lectures throughout the year. These cover a variety of CF topics, such as:

- Genetics
- Nutrition
- Bugs and Drugs
- Holistic Care
- Pain Management
- CF Related Diabetes
- Sinus Disease
- Marriage, Dating and Fertility

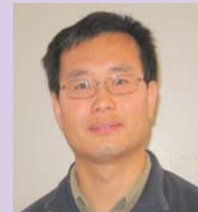
Viewers at a distance can participate in "real" time, texting their questions to the speaker.

Stay tuned: [www.CFRI.org](http://www.CFRI.org)

Cystic Fibrosis Research, Inc. provides vital educational resources to a growing CF community. These include the National CF Family Education Conference, the Teen and Adult Retreat, the monthly CF Discovery Series™, CFRInews™ and DVDs of these presentations.

Publications like "Cystic Fibrosis in the Classroom™", "Fibrosis quistica en el aula™" and "The Cystic Fibrosis Website Guide™" help patients, families, health care providers and teachers be more informed about cystic fibrosis and the needs of those who live with this disease.

## RESEARCH



**Weidong Kong, Ph.D.**  
UC San Francisco  
*Clinical and Basic Research Studies of CF Airway Gland Secretions*



**Yael Gernez, M.D., Ph.D.**  
Stanford University  
*CF-ABPA: An Increasing Threat for CF Patients: Clinically Relevant Tools for Diagnosis and Monitoring*



**Ning Yang M.D., Ph.D.**  
UC San Diego  
*Can We Correct Defective CFTR Induced Abnormal Mucus in CF?*



**Jun Yang, Ph.D.**  
UC Davis  
*Focus on Anti-Inflammatory Therapies for CF with Soluble Exoperoxidase Hydroxylase Inhibitor*

**Daniel J. Hassett, Ph.D.**  
University of Cincinnati  
*Molecular Basis Underlying Killing of Mucoid Pseudomonas aeruginosa by Nitrite*



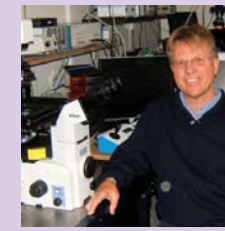
**Jonathan Widdicombe, Ph.D.**  
UC Davis  
*Role of C1 Transport in Secretion of Antimicrobials by Airway Glands*



**Dieter Gruenert, Ph.D.**  
UC San Francisco  
*CFTR Expression Levels and CFTR Function: Transgene Versus Endogenous*



**Terry Machen, Ph.D.**  
UC Berkeley  
*Mechanism and JNK Control of Flagellin-Stimulated Inflammation and CL Secretion by Airway Epithelia*



## ADVOCACY

Cystic Fibrosis Research, Inc. is a strong advocate for all patients and families with CF. We collaborate with notable organizations such as Genetics Policy Institute, California Institute of Regenerative Medicine (CIRM) and others to promote better health for those with genetic disorders.

We support organ donation through efforts such as The Power of Two and Donate Life®.

Through targeted emails and social networking, we post breaking information to those who need it now.

**CFRI** Connecting CF resources with community needs.  
**Celebrate Stem Cell Awareness Day and World Summit**  
On October 5th, patients, advocates, researchers and students around the globe will celebrate Stem Cell Awareness Day in six countries as well as the U.S. with over 25 events at academic and research institutions in California alone.  
Stem Cell Awareness Day  
October 5, 2011 - Get Involved!  
Email blasts such as this carry information and awareness to the CF community.

**babys** FIRST TEST  
Newborn Screening: The Facts  
Most babies are screened for more than 29 conditions.  
GET THE FACTS HOW SCREENING WORKS ADVICE & SUPPORT

Led by Genetic Alliance, CFRI was able to promote awareness and knowledge of Newborn Screening through their new program, "Baby's First Test." Diagnosed early, babies with CF can be treated immediately and look forward to longer and healthier lives.

CFRI informs the CF community of patient financial assistance programs, scholarships and clinical trials. We work with many CF nonprofit organizations, CF clinics and hospitals, academic research institutions and pharmaceutical companies to keep patients up to date.

## Letter from our Executive Director

In 2011, CFRI moved forward in our commitment to connect you with the information you need, so that as an informed patient, you and your health care team can work together to improve life with CF.

CFRI now broadcasts critical, cutting edge CF information to those who need it most. Our streaming programs include the CF Discovery Series™ as well as parts of our National CF Family Educational Conference and our Teen and Adult Retreat. And for those who want to review those presentations, you can order DVDs of the complete Conference, our General Membership Meeting, as well as the CF Discovery Series™ (visit [www.CFRI.org](http://www.CFRI.org)).

In 2011, we continued to fund vital research through the Elizabeth Nash Memorial



will improve the quality of life for those with cystic fibrosis, including gene therapy, stem cell research, integrative medicine, and other important CF medications available and in the pipeline.

Thank you for your encouraging support as we fund CF research and connect CF information and resources with community needs.

Warm Regards,

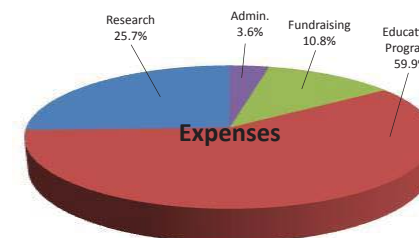
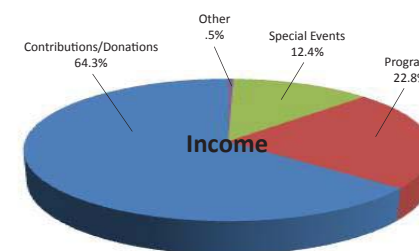
*Carroll Jenkins*

Carroll Jenkins  
Executive Director  
CJenkins@CFRI.org  
650.404.9977

Fellowship Program and our New Horizons Campaign. Researchers are funded for a two-year term, and their publications in prestigious journals cite CFRI's valuable support.

CFRI is pleased to collaborate with other nonprofit organizations. We have promoted effective patient assistance programs from pharmaceuticals and insurance companies. We support a range of potential therapies that

## 2011 Financial Summary



INCOME		
Contributions/Donations	\$601,462	64.3%
Programs	\$212,771	22.8%
Special Events	\$116,125	12.4%
Other	\$4,551	.5%
<b>Total Income*</b>	<b>\$934,909</b>	<b>100%</b>

EXPENSES		
Research	\$209,327	25.7%
Education, Programs	\$486,077	59.9%
Fundraising	\$96,720	10.8%
Administrative	\$28,915	3.6%
<b>Total Expenses*</b>	<b>\$821,039</b>	<b>100%</b>

\*Audited data pending final approval of CPA and CFRI Board of Directors.



CFRI is independently audited by Storek, Carlson and Strutz, CPAs. CFRI is registered as a 501(c)(3) charity: EIN # 51-0169988.