

CFRI – Research and Advocacy Since 1975

Cystic Fibrosis Research, Inc.

CFRI™ 2009 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 gene mutation results in thick mucus that blocks small passage ways in the lungs, intestines and other organs. In addition, infections build. The body needs help to survive. One in thirty-one Americans is a symptomless carrier of cystic fibrosis.

Now, with newborn screening, most people with CF are diagnosed at a very young age. Early treatment makes a big difference in the quality of life with CF.

What Progress Has Been Made Since CF Was First 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 thirty-seven years and growing.

Whom Does CFRI Serve?

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

Hundreds of volunteers assist CFRI to accomplish its mission.

What Programs and Services are Provided?

In 2009, research funded by CFRI increased by over 40%, supporting eight projects that investigate the complex science of this disease – moving CF research forward.

We also provided resources to support the CF community, such as our three-day National Family Education Conference, Teen & Adult Day Retreat, support groups, community outreach and advocacy, educational materials and newsletters.



In 2009, volunteers with the Taproot Foundation created a new website for CFRI and our community. Our thanks to the many people who contributed their time and efforts in service to those challenged by CF.

www.TaprootFoundation.org

On The Cover: Julie and Eric Frisbee have three children, Taylor, Isabella and Trevor. Both Taylor and Isabella have CF.

Eric serves on our Research Advisory Committee and he and Julie attend our National Education Conference.

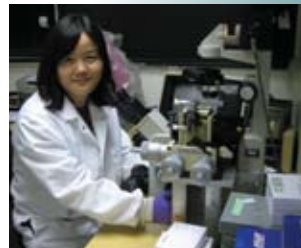
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OUR MISSION:
We exist to fund research,
to provide educational and personal support,
and to spread awareness of cystic fibrosis,
a life-threatening genetic disease.



Michael Cox, Ph.D. – UC San Francisco.
The relationship between CF airway microbiome and pulmonary health.



Ning Yang, Ph.D. – UC San Diego.
Can bicarbonate help mucus release in CF?



Nico Derichs, M.D. – UC San Francisco.
Ex-vivo surrogate assays to assess efficacy of ion channel-targeted CF drugs.



Jun Yang, Ph.D. – UC Davis.
Focus on anti-inflammatory therapies for CF with soluble epoxide hydrolase inhibitor.

CFRI is in an unusual position among nonprofits today. **We are strong and we are growing.**

Thanks to the steadfast support of donors and sponsors, this year we increased cystic fibrosis research funding by over 40%! In addition, we have expanded outreach and support services to those affected by CF.

There are other notable markers of CFRI's growth: Our National CF Family Education Conference hosted 228 attendees from 22 states, including 70 first-time participants. Our CF Teen and Adult Day Retreat was expanded to a full week of activities, and had an increase in attendees.

CFRI News is now mailed to over 15,000 subscribers and other CF organizations have requested permission to reprint our articles.



Our e-mail list is growing and communications are now more effective via our new website launched this past year with the generous support of the Taproot Foundation.

We are contacted by pharmaceuticals and other medical professionals to disseminate information about clinical trials and CF related survey research.

Truly, CFRI makes a difference in the lives of those affected by this disease.

Thanks to one and all for your continuing support of our mission. Your generosity and encouragement inspire us in our work to meet the needs of the CF community.

Warm regards,

Carroll Jenkins

Carroll Jenkins
Executive Director • (650) 404-9977 • cjenkins@cfri.org

RESEARCH is a key element of CFRI's mission. The eight researchers highlighted on these two pages represent the investment your donations make toward advancing the search for a cure.

Research proposals are reviewed by our volunteer Research Advisory Committee to ensure that CFRI funded projects meet the strictest criteria for promising, well-conceived, cutting-edge research.



At our 2009 National Family CF Education Conference, experts shared their findings with 228 attendees from 22 states.



Daniel J. Hassett, Ph.D. – University of Cincinnati.
Molecular basis underlying killing of mucoid Pseudomonas aeruginosa by nitrite.



Forest Rohwer, Ph.D. – San Diego State University.
Metagenomic analysis and microbial communities in CF lungs.

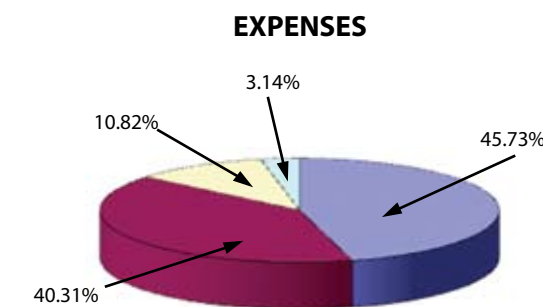
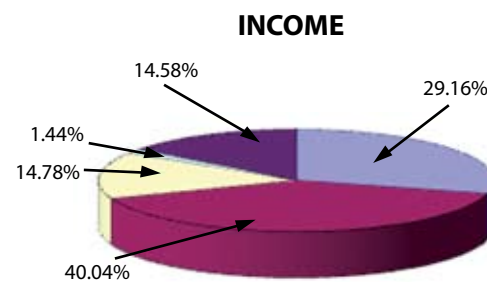


Terry Machen, Ph.D. – UC Berkeley.
Control of flagellin-stimulated inflammation and Cl secretion by airway epithelia.



Dieter Gruenert, Ph.D. – UC San Francisco.
CFTR expression levels and CFTR function: transgene versus endogenous.

Financial Summary: 2009 CFRI Annual Report*



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

Income

Contributions/Donations	\$275,490	29.16%
Solicitations	\$378,311	40.04%
Programs	\$139,612	14.78%
Other	\$13,587	1.44%
Fundraising Events	\$137,764	14.58%
Total Income	\$944,764	100.00%

Expenses

Research	\$485,088	45.73%
Education, Programs	\$427,495	40.31%
Fundraising	\$114,725	10.82%
Administrative	\$33,255	3.14%
Total Expenses	\$1,060,563	100.00%

EDUCATION AND SUPPORT are provided through our National Family CF Education Conference, and Teen and Adult Day Retreat, where attendees hear from CF experts addressing the latest developments in research as well as psychosocial issues. CFRI publishes educational booklets and newsletters, provides support groups, and serves as a key source of information and referral for the CF community.

OUTREACH AND ADVOCACY

are an integral part of our mission. Approximately 30,000 Americans have cystic fibrosis. CFRI works with CF Care Centers, the media and legislature to advocate for those with CF.

A CF patient in Japan poses in front of flags created by California CFRI volunteers to support the Japanese CF community and publicize their profound need for improved care.

CFRI welcomes outreach opportunities to support both national and international CF communities.



Independently audited by Storek, Carlson and Strutz, CPAs.
CFRI is a registered 501 (C)(3) charity: Fed ID 51-0169988



“Connecting CF Resources with Community Needs”