

CFRI news

33 Years of Research, Education & Support

How Research Projects are Chosen

By Rob Robinson

CFRI was founded in 1975 to take advantage of CF research opportunities that were available on the West Coast but were not being tapped.

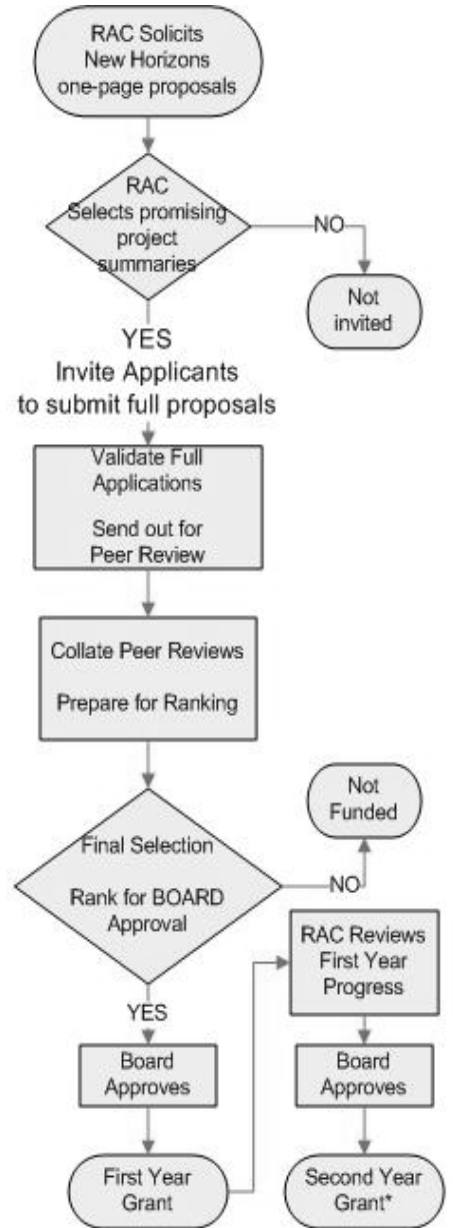
To select and rank the best research proposals for CFRI funding, the Research Advisory Committee (RAC) was created. RAC is a standing volunteer committee of parents, adults with CF, doctors and scientists responsible to our members and Board of Directors. Currently, those serving on the committee include: Marybeth Howard, Ph.D., (Chairperson), Doug Modlin, Ph.D., Valerie Baldwin, M.S., Andrew Hotson, Martin Kharrazi, Ph.D., Terry Machen, Ph.D., Dorsey Bass, M.D.,

Julie Desch, M.D., Gerry Cropp, M.D., Ph.D., Bill Hult (Board Liaison) and myself.

CFRI dedicates a major portion of its budget to help find the cause of and cure for cystic fibrosis. As we grow, the importance of maintaining an effective RAC increases. The number one goal stated in the RAC Policies and Procedures Manual is: *“To fund research of the highest quality that also has the greatest relevance to finding improved treatments or a cure for cystic fibrosis.”*

CFRI currently supports two research programs. In 1999, our Research Fellowship was launched. This has since been

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* CFRI's funding capacity is contingent on annual income.

RESEARCH

Your CFRI Dollars at Work

Summer Update

Investigating Pseudomonas Infections

By Isabel Virella-Lowell, M.D.

According to the Cystic Fibrosis (CF) Registry, over 80% of CF patients suffer from chronic lung infection with *P. aeruginosa* (opportunistic bacteria). Once patients are colonized with



pseudomonas, the airways get progressively more obstructed due to increased inflammation (swelling) of the airway walls and mucus production. *Pseudomonas* finds

an optimal environment in which to live amongst the thick mucus lining the CF airways.

The research performed by my team at the Medical University of South Carolina focuses on identifying the mechanisms behind the predisposition to *pseudomonas* infection and an exaggerated inflammatory response in CF airways. We also look to identify and study potential therapies. These affected patients have an abnormal immune response which includes exaggerated levels of pro-inflammatory cytokines.

Cytokines are proteins that mediate interactions between cells involved in the immune response. Pro-inflammatory cytokines usually are involved in clearing infection by recruiting white blood cells. However, in CF, despite the high levels of cytokines that recruit massive amounts of white cells to the site of infection, *pseudomonas* is not cleared effectively. The

reasons are not completely clear and are part of our investigation. The immune response in CF progresses unabated and the excess number of white blood cells causes swelling and obstruction. This progressive obstruction is the cause of deteriorating lung function. Preliminary work in my lab

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CFRI NEWS 2008 Summer Issue

CFRI News is published and distributed free of charge to friends of CFRI. Send address corrections and other correspondence to: CFRI:
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Notes from Our Executive Director

This issue of *CFRI News* is rich in variety and substance. Our focus on research includes sharing our process for selecting and funding scientific projects.

Since 2001, twenty-six research papers have been published in scientific and medical journals summarizing CF research sponsored by CFRI.

We report on two CFRI founding members in this issue and offer an article on transitioning from pediatric to adult care. One of our current researchers in South Carolina, Dr. Isabel Virella-Lowell, writes of her investigative work on *pseudomonas*. We also summarize a stem cell research conference and include a wealth management article on legacy gifts. Combining effort with two other local organizations, CFRI is excited to announce a new psychotherapy and counseling service available in northern California.

As you read this, volunteers and staff are preparing for our 21st Annual Education Conference and our Teen/Adult Day Retreat in August. For those with CF, your attendance requires a medical release. This information is available on our website and through our office (650) 404-9975. Over 250 attended one or both events last year and attendees have commented that these events can be life changing. At our conference you can ask leaders in research and medical doctors about the latest CF treatments, new medicines and how these may impact you or your

child. The conference includes a CFRI research track where you can meet our researchers as they present current findings.

CFRI is most thankful for our sponsors who make it possible to offer events at the lowest possible costs for attendees. As you may know, over the last forty

years the average age of survival has more than tripled thanks largely to the care-givers, the research and medical communities, and the work of our sponsors.

The cost of registration for our three-day Education Conference is \$150 through July 1st.

Registration for our Day Retreat for five days is just \$65. You may also apply for scholarships for either event at: www.CFRI.org. We'd love for you to join us and I hope to meet you personally in August.

Warmly,



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



Calendar of Events

August 1-3, 2008 CFRI'S 21ST ANNUAL EDUCATION CONFERENCE

"Living a Medical Miracle: CF Today and Tomorrow"
Sofitel San Francisco Bay, California

August 3-8, 2008 CF TEEN & ADULT DAY RETREAT

"Club Med: Retreat of a Lifetime"
Vallombrosa Center, Menlo Park, CA

August 4, 2008 CFRI GOLF TOURNAMENT

Register Now: SHoyt@CinnibarHills.com
or call Scott at (408) 323-7803.

Give Us Feedback

The Newsletter Committee would love to hear from you. On the enclosed envelope is a survey questionnaire. Tell us what you'd like to see more of in future issues; simply rate subjects on a scale of one-to-ten. Results will be published soon. To make additional comments, write them and insert in the envelope, e-mail: DBatchelder@CFRI.org or call Darrell at (650) 404-9978. Thanks for your interest.

TRANSITIONS – FROM A PARENT PERSPECTIVE...

Pediatric to Adult Health Care

By Robin Modlin

From the moment our child was diagnosed with CF, we were assigned an extremely challenging job. It has become part of our identity. When asked, "What do you do?" the first thing that comes to mind is, "I am a CF parent." We also know that it is only another CF parent who can truly understand how all-encompassing this job is.

While our child is young, this job includes managing his or her healthcare. Our lives revolve around health routines. As our child grows up we have to make the transition from being the full-time manager of what feels like critical life-saving decisions to being on the sidelines as a coach. How can this be done gracefully and successfully? It is not acknowledged enough how very difficult and confusing this can be for parents and patients. You are right, it is HARD.

At the magic age of 18 our child becomes an adult. Suddenly, legally we are no longer "the responsible party." Just like that! We are confronted with the HIPPA laws. Now our child (or young adult) has to give permission for us to talk with the medical care personnel. How does a parent prepare to enter this transition period?

Most CF centers have transition programs to help families make this change. But one thing is for sure: each of us and



Alisa and her son, Tommy Evans have worked closely together during their "transition time".

our children are unique. There is no magic method or length of time that it takes for a young adult to assume control of his or her care. With the goal for the child to completely take over his or her health care management, it may have to be gradual changes with a good dose of help and support from parents along the way. The severity of your child's condition may affect the degree to which you continue to be involved. What is most important is to limit your expectations that this transition will happen instantaneously; that your child will never need your guidance and support as an adult; and that your son or daughter is going to flawlessly take over the job that you have been managing for so many years. It will take time. And each young adult will probably do it his or her own way.

Whether your adult child is living at home, at college, or on his or her own, real situations that could arise during this period may include:

- When your child is feeling well all is fine, but once he or she falls ill it can become a huge burden for him or her to manage it all. How are you as a family going to deal with those times?
- If he/she needs to go into the hospital does he/she want you to be there? If so, how can you be his/her advocate? If not, does he or she have an advocate?
- Your adult child may not want you to be involved and may make different choices than you would make. How are you going to cope with this?

It is important during this transition time to communicate. Talk with your child about how hard it is for you. Let your child talk about how it is for him or her, too. Each adult child must learn to shoulder the burden of this disease. This is a big step. How can you work together? How can you still be an advocate and support person for your child? How can he/she begin to take steps to assume the full responsibility without being over burdened?

The following are my transition tips:

1. Write everything down that needs to be done. Have a check list, and create a schedule.
2. Simplify the routines and prescriptions. Use home delivery services.
3. Organize medications one month at a time. Use pill boxes.
4. Do not step out of the picture abruptly. Make it gradual. It will probably take longer than you expect. Continue to reach out and let him/her know you are available to help or consult.
5. Discuss possible future scenarios such as what will happen during a hospitalization or period of home

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Two Additional Tips:

- Begin the transition as soon as you see that your children or teens can start to take charge of some CF chores. Teach them to sort their meds and sterilize their nebulizers. Begin to stop hovering at "treatment time." Encourage them to talk with their healthcare providers telling them the list of meds they are on and describing how they are feeling.
- It is important to consider the current health circumstances of your child when discussing future scenarios. One parent and her teen had discussed different college possibilities, dorms, junior colleges, etc. Most of this discussion was when her child was well, and not under pressure. It helped to revisit some of the decisions about future college plans after a recent health crisis. Her son rethought his expectations of himself. It was very interesting to see what changed in terms of what he thought he could handle. He realized he needed to be closer to home and the hospital.

State of Stem Cell Advocacy Conference in San Francisco

By Siri Vaeth-Dunn

Over 100 million Americans suffer from chronic disease or permanent disability at a treatment cost of \$1.3 trillion per year. Stem cell research offers the promise of cures for many of these diseases. On April 12 and 13, the Americans for Cures Foundation held the 2008 State of Stem Cell Advocacy Conference where researchers, disease advocates and clinicians from across the country gathered to learn about recent progress towards cures in several disease areas, as well as what specific actions patients and advocates may pursue to advance stem cell research.

CFRI was a supporting sponsor of the event, which was held at San Francisco's UCSF Mission Bay Conference Center. CFRI Board Member Siri Vaeth-Dunn served on a panel titled "You Can Make a Difference," where disease advocates shared ways in which they have advocated for stem cell research personally and through their organizations.

CFRI was one of the first organizations to endorse Proposition 71 in 2004, which created the California Institute of Regenerative Medicine (CIRM), granting \$3 billion in stem cell research funding to California institutions over 10 years. Since then, the CIRM governing board has approved 156 research grants totaling almost \$260 million, making it the largest

source of funding for embryonic stem cell research in the world. While cystic fibrosis may not benefit from a stem cell cure in the near future, there are many ways in which people with CF will be positively impacted, including improvements in drug testing, diabetes treatments and the potential to reduce organ transplant rejection.

The Americans For Cures Foundation is a nonpartisan 501(c) (3) organization, whose mission is to support fellow advocates in the fight for stem cell research and cures. While the benefits of stem cell research are clear, there are many organized attempts to halt this research. The conference provided participants with concrete tools and strategies to bring back to their respective fields and communities to advance both political will and funding for research.

For more information about the Americans for Cures Foundation, visit their website at www.americansforcures.org. On their homepage you will see a video made by the Foundation, called "Mothers of Children with Cystic Fibrosis," which features CFRI's Carroll Jenkins, Ann Robinson, Kristie Dobson, Sydney Altano and Siri Vaeth-Dunn.



Amy Daly, Co-Executive Director, Americans for Cures Foundation, (R) and CFRI Board Member, Siri Vaeth-Dunn, (L) were two participants on an "Advocacy" panel during a two-day State of Stem Cell Advocacy Conference held in San Francisco in April. This group supported California's Proposition 71, endorsing Stem Cell Research. On May 7, 2008, CIRM awarded over \$270 million dollars in grants to build stem cell laboratories in California.

21st Annual CFRI Education Conference

REGISTER NOW
www.CFRI.org (650) 404-9975

CFRI and the United States Adult Cystic Fibrosis Association (USACFA) are proud to present *Living a Medical Miracle: CF Today and Tomorrow* to be held August 1-3, 2008 at the lovely Sofitel in Redwood City, CA, located just 20 minutes south of San Francisco Airport. A new feature this year is our pre-conference orientation for newcomers. CFRI staff and volunteers will navigate you through the conference sessions, share our Hospitality room (the Black Pearl Lounge) and direct you to our sponsors.

Medical safety is our priority, so every year people with CF are required to submit a medical release, signed by their physician (please see www.cfri.org site or our registration form for details). In keeping with our tradition of offering financial aid, scholarships are available for eligible participants. Contact us at: cfri@cfri.org, website: www.cfri.org or call (650) 404-9975. Reserve your place now for what is sure to be a weekend full of education, camaraderie, knowledge-gathering, and kick-up-your-heels fun.

CF Courage Dolls at Conference

A new community project will debut at the conference in August. CF Courage Dolls will be on display in the Veranda room. Between October 2007 and June 2008, 7 mothers, one stepmom and one aunt of a child with CF created these works of art and support. Each month a new task was assigned (a head, arms, legs, etc) and each month a different doll was worked on by each woman. A monthly journal entry about the dolls' journey tells the story and what each doll offers. This process kept them thinking about each other and what someone with CF in the family needs to meet each day. The result is a collection of artistic and symbolic dolls with deeply meaningful images and words of wisdom. Be sure to drop by and say "hello" during the conference.



**Cystic Fibrosis Research, Inc.
21st Annual Education Conference**

**Register
Now**



***Living A Medical Miracle:
CF Today and Tomorrow***

August 1-3, 2008
Sofitel San Francisco Bay
Redwood City, California

For more information, please contact:
Cystic Fibrosis Research, Inc. (650) 404-9975
cfri@cfri.org www.cfri.org

In collaboration with United States Adult Cystic Fibrosis Association (USACFA)

Presentations and Speakers Include:

“Improving Lung Function By Controlling Infection”

Richard H. Simon, MD, University of Michigan, Ann Arbor, MI

“Cystic Fibrosis Related Diabetes”

Dana S. Hardin, MD, Nationwide Children’s Hospital, Columbus, OH

“Exciting Progress in Cystic Fibrosis Research”

Carlos Milla, MD, Stanford University Medical Center, Stanford, CA

“Strategies to Reduce Time For Airway Clearance”

Mark R. Elkins, PhD, Royal Prince Alfred Hospital, Sydney, Australia

“Complementary and Alternative Medicine”

John D. Mark, MD, Lucile Packard Children’s Hospital, Stanford, CA

“CFRI Research: The New Horizons Campaign”

Marybeth Howard, PhD, University of California San Francisco, CA

“CFRI Research: The Elizabeth Nash Memorial Fellowship”

Jonathan Widdicombe, PhD, University of California Davis, CA

“Sexuality and Reproduction in Cystic Fibrosis”

Anna O. Tsang, RN, NP, MSN, St. Michael’s Hospital, Toronto, Canada

“Compliance”

Joseph Solowiejczyk, RN, MSW, CDE, Animas Corp., Los Altos, CA

“Say What? Explaining Medical Care to Children with CF”

Courtney Moreland, BS, CCLS and Debra Monzack, BSed, CCLS, Lucile Packard Children’s Hospital, Palo Alto, CA

“Sick Girl Speaks!”

Tiffany Christensen, Author and Patient Advocate with CF, Chapel Hill, NC

Early Bird Special Registration on or before 7/1/08: \$150 per person (includes meals)

Regular Registration after 7/1/08: \$175 per person (includes meals)

Scholarships are available but limited to eligible applicants.

Doors Open to Quality of Life

Counseling and Psychotherapy Services Designed for the CF Community

By Bridget Barnes

CFRI is excited to announce the opening of the Cystic Fibrosis Quality of Life Program: A Living Legacy of Peter Judge. CFRI, The Center for Education in Family and Community Medicine at Stanford University, and the Institute of Transpersonal Psychology (ITP) in Palo Alto, CA., all contributed to the program's design.

Psychotherapists at the Transpersonal Counseling Center (TCC), a division of ITP, launched the program in April. They provide counseling and psychotherapy

services to those affected by cystic fibrosis, including those with CF, their parents, siblings, children and caregivers. This visionary program involves the integrative care of body, mind and spirit.

TCC counselors and psychotherapists address everyday issues such as communication, grief, anger, time management and depression. And, they are in touch with how these issues might be particularly challenging for those in the CF community.

Doctoral interns at TCC completed a six-month training program designed to orient them to the CF community during which time they heard from adults with CF, parents, therapists and psychologists.

All at TCC recognize that cross-infection issues are very important for those with CF. In fact, the same cross-infection protocols implemented at our annual education conference are observed at TCC. (If you have MRSA or *B. cepacia*, telephone counseling is available.) While the program currently serves residents in the San Francisco Bay Area, it is being designed to serve as a model with the larger CF community in mind.

Fees are based on a sliding scale; no one will be turned away for lack of funds. To make an appointment, please call (650) 493-5006 ext. 224.

A Retreat from the Norm:



Board members attending (left to right), Bill Hult, JoAnn Davis, President; Bridget Barnes, Scott Hoyt, Treasurer; Siri Vaeth-Dunn, Jessica Martens, Secretary; and Mike Roanhaus.

On Saturday, January 12th, members of CFRI's Board of Directors gathered to discuss the organization's short and long-term goals. The retreat offered Directors the opportunity to share ideas without the time constraints faced during monthly Board meetings. Key topics included: a review of CFRI's budget; the participation of CFRI's membership in organizational research funding decisions; and ways in which the Board can further its results-oriented direction and leadership.

Another topic was the importance of refining CFRI's "niche" in the CF community. Board members appraised CFRI's unique role in funding key CF research and providing education and support to those living with CF. They discussed how to assist those families whose babies are newly diagnosed through new-born screening programs and reflected on potential activities to assist those for whom English is a second language.

CFRI Board of Directors Holds Annual Planning Retreat



JoAnn Davis (center) reviews a CF organization's web site with Scott Hoyt and Bridget Barnes.

The Board is comprised of parents of children with cystic fibrosis, an adult with CF, and others who are friends and advocates for the CF community. This annual retreat from the norm of monthly meetings provided Directors with renewed inspiration and enthusiasm to effectively oversee the critical work of CFRI.



Cystic Fibrosis Research, Inc.

21st Annual Education Conference

Photograph Exhibit

Join Our String of Pearls!



Our conference this year is entitled ***Living a Medical Miracle: CF Today and Tomorrow.***
With this in mind, we are very excited about our Conference Photograph Exhibit - *Won't you join us?*

If you or a relative has cystic fibrosis, we would love to have your photograph in our Pearl Gallery at
CFRI's 21st Annual Education Conference (August 1-3, 2008).

Photographs are being accepted from across the country, and around the world!

We would also love to have your input on the following two thoughts:

1. It feels like a miracle that living with CF, I can/my child can:

(Example: ride a bike, play the drums, graduate, climb a mountain, enter a speech contest, be in a parade...)

2. I believe I have helped make this happen by:

(Example: staying compliant with my medications, staying in touch with my medical team, taking on a new hobby, exercising...)

There is no age limit - here's how to participate -- SEND:

1. Your 5" x 6" or 5" x 7" photograph (.jpg format is preferred)

2. Your name and address

3. Your input on the two thoughts listed above

To: cfri@cfri.org (email is preferred)
or CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043, USA

The deadline to submit your photo and information is Friday, July 4, 2008.

By sending in your photograph, you agree that your entry may be photographed or videotaped to share with others.

Photos will not be returned. Questions? (650) 404-9975 or cfri@cfri.org

We look forward to including you in our *String of Pearls!*

How Research Projects are Chosen
(continued from page 1)

renamed the **Elizabeth Nash Memorial Fellowship** in honor of Elizabeth Nash, who served as RAC chairperson in 2002. Liz had a Ph.D. in genetics and pursued a rich variety of interests with dedicated energy, not allowing CF to limit her reach. Liz passed away in 2003. This program named for her supports promising new investigators and fosters collaboration among researchers as they pursue critical research at well recognized CF laboratories.

In 2006, CFRI funding for research expanded, thanks to the generosity of our donors. This additional funding was dedicated to a new program: **New Horizons Research Campaign**.

Projects funded by CFRI are listed on our website under “Research”: www.CFRI.org.

RAC Responsibilities

CFRI research funding is approved annually at our General Membership Meeting. RAC’s main job is to oversee how the organization’s research funding is spent. RAC is responsible for soliciting, evaluating and ranking proposals for the **New Horizons Research Campaign**. They ensure the integrity of the research through a peer-review process, and

confer at length before proposing recommendations to the Board of Directors. (See flow chart for the overall flow of reviewing and granting research on page one.)

RAC also provides oversight for the **Elizabeth Nash Memorial Fellowship**. Research projects of two years duration are solicited periodically. Under guidance of Jonathan Widdicombe, Ph.D., the projects are sent out for peer review and then ranked for RAC’s consideration. In 2007, a three-person Fellowship Steering Committee composed of scientists and doctors was formed to assess the ongoing research conducted by the fellows and provide constructive feedback. After one year, all projects are re-evaluated by both RAC and the Board to determine if they qualify for second-year funding.

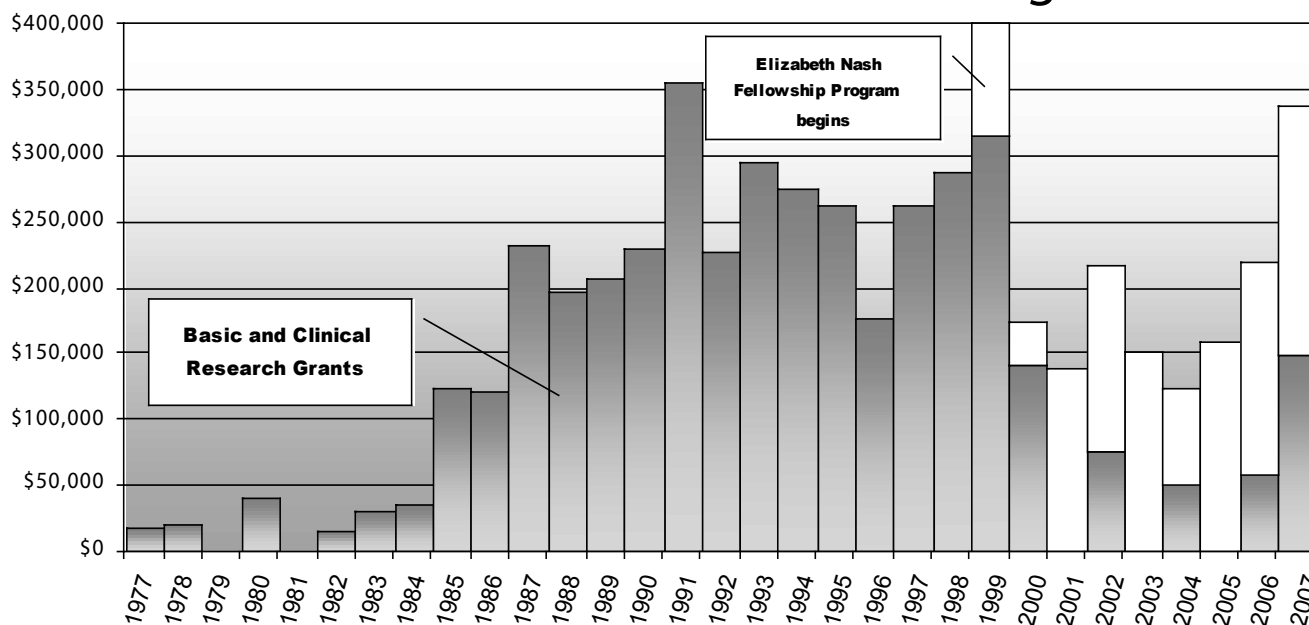
Post-doctoral fellows and their principle investigators meet in colloquia semi-annually to share their progress. One of the two meetings takes place as the “Research Track” of CFRI’s Annual Education Conference. The fellows and their principle investigators co-author articles for publication in medical and scientific research journals. (See *CFRI News* Summer 2007 issue for more information about the fellowship program.)

Since 2001, the **Elizabeth Nash Memorial Fellowship** has funded many projects. Our researchers have subsequently published twenty-six separate articles in prestigious medical and scientific journals.

Marybeth Howard, Ph.D. currently serves as volunteer RAC chairperson. She is an established CF research professional who received CFRI funding in prior years. Modern CF research is extremely complex and conducted by hundreds of bright investigators. Dr. Howard brings her experience and commitment as a researcher in the field to give valuable guidance to the committee. In turn, the committee, particularly the chairperson, relies on extensive assistance from CFRI staff for co-ordination and administration. Past RAC chairpersons include Doug Modlin, Ph.D., Michael Silver, Meg Delano, M.D., Burt Jones, Ph.D., Elizabeth Nash, Ph.D., and Valerie Baldwin, M.S.

The RAC welcomes additional members to our committee, preferably medical doctors and bio-scientists. Their critical input will continue to help us select research projects which will contribute new and relevant understandings of CF to the scientific and medical community.

CFRI Dollars Granted for CF Research Through the Years



RESEARCH PROJECTS

What Gets Funded?

By Darrell Batchelder

What research will be funded by CFRI? It is a complex question. In our mission to support excellent CF research, CFRI requests proposals from the CF research community periodically. Whether for the **Elizabeth Nash Memorial Fellowship** or the **New Horizons Research Campaign**, each proposal is reviewed by the Research Advisory Committee (RAC). These proposals are all subject to peer review by experts in relevant scientific fields. In the end, which projects will RAC recommend supporting? They use a multi-stepped, disciplined process to seek answers to relevant questions.

Questions include: "Is this good science? Does the project take into account previous efforts of the scientific community? Do the budget and timeframe realistically reflect the goals to be accomplished? Does the researcher have adequate support in his/her laboratory?" Other questions: "How is this specifically relevant to CF and what will be the benefits to the CF community? Has this laboratory conducted research in this field before? Has good science come from previous studies?"

"Are other funds currently supporting this specific research?" Sometimes the committee considers 'bridge funding,' providing funds to complete a phase of research so the project can qualify for alternative funding. Additional consideration is given to new and unique avenues of inquiry. What's important to our process is that everyone with a serious proposal is considered. Annual project grants average \$40k-\$75k per year. Currently we fund seven research projects through CFRI's **New Horizons** and **Elizabeth Nash Memorial Fellowship**.



What Is Our CF Research Niche?

The process of creating a CF drug and making it available to consumers at the pharmacy is considerable. It usually begins in laboratories where scientists study the basic building blocks of CF. New understandings of this disease continue to be discovered around the world. Then, the process moves through stages of "basic" lab science and eventually into phases of clinical trials.

CFRI has traditionally invested in laboratory science. Our funding increases the foundational knowledge that is essential for drug development. The advanced clinical trials that can involve hundreds of people testing a drug are a product of the basic understandings of the disease and how it works.

Once our research projects are completed and findings announced, published research results are shared through the internet which allows them to be replicated and new questions posed. If there are promising avenues for development of treatments or drugs, larger organizations or pharmaceutical companies may step in to take the research to the next level of testing.

As we grow, CFRI is able to increase and diversify our support of cystic fibrosis research. While we may or may not fund the exact breakthrough project that leads to our ultimate goal, we contribute to the understanding of this disease. We are making critical contributions to a body of world-wide research – a CF scientific mosaic – that will bring about a cure.

Thank you one and all for your continued support of CFRI! Your contributions make a cure possible.

Darrell Batchelder and Rob Robinson (r) share a story and laugh at last year's CFRI Education Conference. Rob has served on the RAC for over ten years. Darrell works part time at CFRI.

Congress Passes Landmark Law

By Darrell Batchelder

On April 23rd, 2008, lawmakers of the House of Representatives voted to make it illegal for employers and insurance companies to deny applicants jobs or health care coverage based on DNA tests that might show they are genetically disposed to a disease, such as being a CF carrier. The law, H.R. 493, the Genetic Information Discrimination Act, forbids sponsors of health coverage from requesting or using genetic information to adjust premiums or to determine eligibility. It would also prohibit employers from using this genetic data in hiring, firing, assignment or promotional decisions. On April 30th the Senate voted unanimously for the bill. The White House has indicated its support and the President is expected to sign it as we go to press.

This bill came about because the human genome project was declared complete about five years ago. Working independently, two teams of scientists identified the three billion sequence, or building blocks made up of our four-letter DNA human alphabet: A, C, G, and T. While each individual is unique, it's the sequence of these letters and how they follow each other that makes each of us slightly different. Why is this important? Over the last three years in particular, scientists have begun comparing the human genome sequence of "healthy" people vs. those who have a specific disease or condition. Many people have been reluctant to get genetic testing or participate in medical studies if their DNA might be revealed to insurers or employers. This reluctance delays research.

For instance, the March issue of the Journal of the American Medical Association reports that gene-scanning techniques have linked nearly 100 DNA variants to as many as 40 common diseases and traits. In just one day last February, three separate research groups reported finding several generic variants tied to the risk of prostate cancer. Scientists have reported similar results for conditions ranging from heart attack, multiple sclerosis to gallstones. The list even includes restless leg syndrome. This legislation paves the way for more individual DNA testing without fear of reprisal from employers or insurers.

Creating Your Legacy through Charitable Giving

Nonprofit organizations are able to serve their communities because of the generous support of donors like you. Many options are available for making a financial contribution, and these are sometimes overlooked when they might well be to the donor's advantage. All tax deductions are subject to state and federal tax laws.

Direct gifts of cash or checks can be considered a tax credit, if the receiving charity is a 501(c) (3) organization. These charities will be able to provide you with a Federal Tax ID number. The amount of your tax credit is the amount of the donation less the value of any goods or services received from the charity.

Ongoing monthly or annual gifts provide a charity with predictable income that helps them plan. These can be automatically deducted from a bank account or distributed periodically by funds or foundations.

An additional option is the charitable gift of life insurance you may no longer

need. You may find you can sell it for cash now, receive monthly income, or make your favorite charity the beneficiary when your estate is settled. There are professionals who specialize in this type of gift.

Some donors wish to leave a legacy to an organization by establishing a trust. To set this up, it is important to consult a CPA, banker, financial planner or estate planning attorney. These professionals may charge a fee for their services. At the same time, trusts often offer favorable tax consequences which pay for the investment. The process may be as easy as adding a few sentences to your will. Here is one example of a simple bequest paragraph: **"I give [__% of my estate] or [\$__ specific amount__] to: Name and Address of Charity, and the Charity's Federal Tax ID number.**

CFRI does not offer legal advice. In all cases you should discuss your wishes with a trusted professional who specializes in trusts, wills and/or estate planning.

Enhanced Vehicle Donation Program

Now Available Throughout The United States

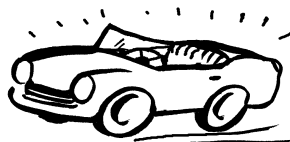
Help CFRI by donating your car, truck, motorcycle, boat or RV. Your tax-deductible vehicle donation funds lifesaving research and educational programs that prolong the lives of children and adults with CF and move closer to our goal of finding a cure for cystic fibrosis. Our enhanced new program makes it easy and convenient.

You make the call, arrange a convenient appointment time, have the keys and pink

slip ready and someone will arrive to take your vehicle (or tow it).

E-mail cfri@cfri.org or call (650) 404-9975 for more information.

*It's Easy.
Free Pickup.
Running or Not.
No Hassle.
We Handle It All.
Tax Deductible.*



Four Stars!



Today's donors have a variety of tools to help them select a charity for their contributions. There are almost one million, four hundred thousand charities in the United States and this number has doubled since 1996! Which charity will you support? Some organizations now rate charities based on a number of factors. How much is spent in the charity's administrative overhead and fundraising? Of a dollar given, how much goes directly for programs to aid the charity's main goal or mission?

One such independent guide is GuideStar – www.GuideStar.org. While it does not rank charities it does review all financials and post summaries for donor review. Another guide is www.CharityNavigator.org. Like a Zagat or Michelin critic who rates restaurants and hotels, Charity Navigator ranks charities from one star (lowest) to four stars (highest). Only twenty-nine percent of charities reviewed earned a four-star ranking this year. CFRI is proud to be awarded four stars and continues to be an effective steward of your donations. Whichever charity you choose, it is often helpful to have an independent third-party analysis to support your decision.



Providing Pertinent Information on 501 (c) (3) Nonprofit Organizations.



www.CharityNavigator.org, the web's guide to "Intelligent Giving," gave CFRI their highest rating.

OUR FOUNDERS

Heath and Gail Wakelee

By Ann Robinson

When Heath Wakelee was a student at the University of Santa Clara in 1973, he began looking for a place to volunteer for a nonprofit organization that assisted children. The Volunteer Bureau of Santa Clara referred him and his wife Gail to CFRI. Even though Heath and Gail have no CF in their family, they began a long, sustained commitment. They were attracted to CF because it was a grass roots organization. At that time, CFRI was made up of parents, grandparents and friends, with cystic fibrosis being the common bond. This dedicated group would do anything for their children and whatever anyone did was sincerely appreciated.

At their first meeting held in a small office on Neal Avenue in San Jose, they joined about 10 people sitting around tables making gift tags. These were packed into small cellophane bags and sold to their friends and neighbors for \$1 each. CFRI meetings were work parties where everyone pitched in. Other early fundraising events included a karate tournament, a horse show and rummage sales.

Once a month, eight to ten CFRI members would gather to discuss raising money, recruiting members and sharing concerns about their families. The group had many concerns. "How can we keep growing? How can we raise enough money for CF research? How can we find the best research to fund?" Heath was instrumental in

helping file CFRI's 501 (c) (3) nonprofit incorporation papers in 1975.

Heath and Gail held various board offices with Heath serving as President and Vice President and Gail serving as Treasurer. Gail chaired the Mothers' Day Tea, Rummage Sales, and Christmas Boutiques. Heath and Gail also chaired the first Silicon Valley Invitational Golf Tournament held at Stanford University for CFRI.

In April, 1988, Heath led a group of 14 children with CF and their parents on a weekend camping trip to the Pinnacles. The group learned about nature from a naturalist who enriched their experience. At the end of the trip, Heath was given a silver key bob that he still carries with him today – it reads, "To: Chief Lost In the Woods – From: Happy Campers."

After funding the research of Paul Quinton in 1979, the Wakelees and the CFRI community were excited that Paul went on to discover the CF chloride channel defect in 1982! When the CF gene was discovered in 1989, we were thrilled to know that CFRI played an important role in CF gene discovery. In 1998, Gail and Heath moved to Rocklin, CA. Gail "retired" a few years ago while Heath continues to sell test and measurement instruments. Currently, Heath is President of the Sierra Foothills Audubon

Society and an active volunteer for the American Red Cross. Heath also supervises his 92 year old father's care and enjoys fly fishing and backpacking in his "spare" time. Gail actively participates in AAUW and in many social activities.

Thank you, Heath and Gail, for your caring dedication to our CF community!



24th Annual CFRI Golf Tournament

Monday, August 4th, 2008
Cinnabar Hills Golf Club
23600 McKean Road
San Jose, CA 95141

Our largest sporting event of the year includes 18-holes of golf, wine tasting, silent auction, hors d'oeuvres, and an excellent venue – Cinnabar Hills. All proceeds go directly to support CFRI's mission. Your investment for a great day: only \$225. Sponsorship packages are available.

Register today by phone or e-mail. For more information call: Scott Hoyt at (408) 323-7803 or SHoyt@CinnabarHills.com

Volunteers Appreciated!

CFRI "runs" on the volunteer efforts of hundreds of supporters – from our nationwide volunteer Mothers' Day Tea senders to those who advocate for CF in their daily lives.

Some members and friends have submitted articles for *CFRI News*; others assist here at the office. If you live in the SF Bay Area and have extra time this summer, we'd love to *appreciate you*.

Volunteer Opportunities:

- Mailing materials for our *Annual Education Conference* or *Mothers' Day Tea*
- Helping to write special Thank You notes
- Updating CF resources for *CFRI's Cystic Fibrosis Web Site Guide*
- Calling CFRI members
- Assisting at Special Events

There is a lot of variety and you can choose those volunteer areas that best fit your talents and expertise. If you can contribute two or three hours, call Mary at (650) 404-9975 to find out more. Volunteers are invited to our Volunteer Hospitality Party held each year between Thanksgiving and Christmas, too!

ANNOUNCING THE CYSTIC FIBROSIS TEEN & ADULT DAY RETREAT

August 3 – August 8, 2008

Located at Vallombrosa Center in Menlo Park, California

This Year's Theme:

CF Club Med: Retreat of a Lifetime!



Meet Some Great Friends!
Feel Like You're Not Alone!
Learn more about taking care of your CF!
This is a place for hope and healing!



Who Can Come: Teens and adults 15 years and older with cystic fibrosis; their family members, friends and health care providers

Purpose of the Day Retreat: The retreat provides a safe and welcoming environment aimed at enhancing positive coping skills, social support and education for people who share common experiences with CF.

What We Do: Activities that promote health include daily exercise, arts and crafts, rap sessions, and educational workshops with guest speakers. Fun group-bonding activities include a talent show, games, and just hanging out getting to know others.

Cost: \$65 per person for the entire week. Daily fees are \$15 per day for visitors or \$10 per meal for those who drop in for a meal only. Overnight accommodations and transportation are the responsibility of participants. Scholarships are available for those unable to pay fees.

Safety: All people with CF are required to comply with cross infection behavioral precautions. A medical advisor is available at all times, and volunteers are available to assist with respiratory treatments. Participants with CF must obtain a sputum culture before the start of the retreat.

Those who have ever cultured *Burkholderia cepacia*, cultured Methicillin-Resistant *Staphylococcus aureus* (MRSA) within the past 2 years, or are currently resistant to all antibiotics will not be allowed to attend the retreat.

We'd Love To See You There! Register Today

For An Application, Please Contact:
Cystic Fibrosis Research, Inc.

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

Phone: (650) 404-9975 cfri@cfri.org Fax: (650) 404-9981 www.cfri.org

2008 Teen/Adult Day Retreat

REGISTER NOW
www.CFRI.org (650) 404-9975

Attending CFRI's Retreat may be a life-changing experience. Read what attendees have said about past conferences... then register. Scholarships are available. We follow strict health guidelines (see flyer) and the Day Retreat registration does not include overnight lodging. Call our office for additional accommodation information.

The CFRI Retreat is a very special place where people with CF and their loved ones gather once a year for a week of camaraderie and support. I wait all year for this because it provides me a safe place where I can share my feelings and concerns among a group of peers who really understand. I learn more about living and surviving with CF from this group than I ever do from health care providers. I truly believe that I am alive today because of the support and skills I have gained here.

–34 year old female with CF

I came here hoping to make a network of friends and I ended up with family. In one way or another each became a mother, father, brother, or sister to me. Ya'll have talked about cystic fibrosis in a way that I never knew existed. The openness, the freedom to laugh and cry and the sincerity of the stories and talks I have had makes me want to live even more. For the first time in my life I feel connected with the world around me. I have spent 22 years alone in a body. We each have our own pain, but somehow we all share the same pains in different ways. The greatest way I have seen people caring is the laughing and sharing themselves. I have spent every night up talking late with someone about what is on my mind and they simply just got me.

–22 year old male with CF

Brewing a Cure For Cystic Fibrosis

By Bridget Barnes

It's that time of year again when dedicated friends and staff of CFRI invite their loved ones to participate in our biggest annual fundraiser – the Mothers' Day Tea.

Invitations are being sent from a very dedicated and efficient group of volunteers and staff. CFRI received its first donation of 2008 on April 4th. Since then, tea senders have responded from over 44 states as well as from the emerald isle of Ireland. Our goal this year is \$283,000 to support research and programs instrumental in improving and expanding the lives of people with CF. Your dollars are critical in funding CFRI's research, outreach and educational programs such as the annual Education Conference and Teen/Adult Day Retreat, *CF in the Classroom*, the *CF Website Guide*, and *CFRI News*.

When you receive your invitation, please enjoy a cup of this year's "Perfect Peach" tea (donated by Bigelow) and consider making a donation. If you want to become a tea sender, it's not too late. For complete packets including invitations, envelopes, tea bags and

mailing labels, please call our office: (650) 404-9975 or email: CFRI@cfri.org. Thank you!



Julie Judge, mother of the late Peter Judge, took home a beautiful Spode teapot which she won through the Mothers' Day Tea Kick-Off Raffle in March.

Readers of this newsletter may purchase premium wines at reduced prices.

At the same time, CFRI receives 15% of the purchase price as a donation.

Mmm, Mmm, a fun Win-Win for everyone. You must be 21 to order or accept wine deliveries.



CFRI –Join Our Wine Club!

If you enjoy premium wines at affordable prices, CFRI has discovered a Monterey County winemaker who shares your wish. Chateau Marie Antoinette offers CFRI members discounts of 10%, 15% and 30% for wines—several rated in the low 90's by expert sommeliers. What's more, any wine ordered through our program will result in an additional 15% contribution to CFRI from the winery. Delivery included!

Questions: Call (650) 404-9978

In Memory of

(Contributions listed were received from
March 1, 2008 to April 30, 2008)

"In Memory of" lists names of loved ones we have lost, and in whose memory a donation has been made.

We extend our deepest sympathy to their families and friends. These gifts continue to give hope to children and adults with cystic fibrosis. "In Memory of" is not only for those with CF but for their families and relatives as well.

Note: Occasionally a deceased person will have the same name as a living person.

Send the name of your lost loved one with address of the relative/spouse, etc. that you would like to receive an acknowledgement of your donation.

Send to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043.

Cliff	Laura Gale	Betten Marks	Louise M. Schroeder
Tommy	Julie Gardner's father	Alzira Medeiros	Stephanie Southworth
Carol Adelman	Teresa Giuliani	Humberto Medeiros	Gilda Stagnaro
Fern Adelman	Isaac Saul Goldman	Louiz Medeiros	Rev. Carl Stolley
Kim Adelman	Douglas Graham	Manuel Medeiros	Dave Stuckert
Marcus Adelman	Jeni Hall	Marion Medeiros	Laurie Stuckert
Rosemary Altano	Stephanie Halling	Jessica Mobley	Mel Stuckert
Frank "Rocky" Avalos	Lucille K. Halvig	Jennifer Montgomery	Shane Summers
Iona (Rusty) Baffoni	Francine Hamilton	Lorraine Mulneaux	Ann Marie Thibault
Anne C. Beltrame	Warren Harden	Elizabeth Nash	Patricia Thibault
James W. Bertolini	Nancy Holbrook	Josephine Nelson	John Trask
Beatrice Bianchi	John Holmes	Kim Nelson	Louis Anthony Trigueiro
Carolyn Burroni Warner	Mark Holmes	Marilyn Nelson	Jennifer Uskoski
Thelma Cady	Tracy Holmes	Marvin Nelson	Erik Van Ness
Sonya Chartrand	Hayley Horn	Scott Nelson	Jody Voller
Ryan Coelho	Leslie Hotson	Irene Nestle	Mary Vrelab
Desiree Contreras	Dr. David Ichelson	Tony Nickeson	Tom Walton
Rachel Crocker	Peter Judge	Jennifer Ortmann	Sean Waltrip
Diana Da Mota	Kathy Judge Morse	Sean O'Sullivan	Edward Weigert
Josh Dadami	Leslie Kalbach	Barbara L. Palys	Tina Williams Crow
Caroline Daly	Ray Knudsen	Lucian, Pinkney Jr.	Kelly A. Wilson
Beth Dauphinais Selsor	Jennai Kodis	Peter Pinkney	Virginia Wingate
Beverly Detrick	Phil Kosloff	Jon Prater	Diamond Woodworth
Marty Detrick	William Laird	Tim Prater	
Marvin Detrick & Family	Donn Lando	Holli Pratt	
Neva-Louise DeVore	Janice Lando Gregory	Catherine M. Rawlings	
Joseph Dito	Lucille Lensson Marsh	Trevor Rickenbach Fenn	
Barbara Dittrick	Dawn Longero	Billy Ruffner	
Mary Eddy	Jennifer Longoria	John Runge	
Betty Edwards	Bob Mackey	Randy Ruprecht	
Gene Ergas	Dr. Sidney Malet	Melvin Sachs	
Boyd Faulk	Ron Mardigian	Dhea Schalles	
Pam Faulk	Allen Marks	Linda Jeanne Scherschel	



Investigating *Pseudomonas* Infection (continued from page 1)

looking at the differences between CF and non-CF cell gene production during *pseudomonas* infection led us to look at the role of lipids (fats) in *pseudomonas* infection. Lipids are known to play an important role in cell growth and immune regulation.

Specifically, we are interested in acid sphingomyelinase (ASMase), a key enzyme in lipid metabolism which can be activated by bacteria. We were able to demonstrate that while non-CF cells and mice respond to *pseudomonas* infections with an increase in ASMase production, CF patient cells grown in tissue culture and cells located in the CF mouse airways do not increase ASMase production. In CF cells and mice, the RNA coding for ASMase production was lower, as were

ASMase protein levels and enzyme activity. ASMase is necessary for the production of a lipid called ceramide which is involved in the formation of rafts at the cell surface that bind and help eliminate bacteria. Total ceramide levels significantly increased with *P. aeruginosa* infection in normal airway cells but not in CF cells.

Our studies also demonstrated that the induction of ASMase is responsible for attenuating the pro-inflammatory cytokine response, post bacterial infection. Blocking ASMase activity in non CF-cells significantly increased the levels of the pro-inflammatory cytokine, IL-8, with *P. aeruginosa* infection. Reciprocally, adding ASMase to CF cells significantly decreased IL-8 levels compared with untreated cells. Silencing of ASMase in non-

CF cells also significantly decreased the amount of bacteria ingested and cleared by the airway (epithelial) cells. We found a two-fold difference in bacterial uptake between CF cells and non-CF cells after *P. aeruginosa* infection. Additionally, twice as many of the non-CF cells died after bacterial ingestion thus effectively clearing the *pseudomonas*. Taking into account the increased amount of cell death in non-CF cells, the difference of ingested bacteria between cell lines is approximately four-fold. "Silencing ASMase activity in non-CF cells significantly decreased the amount of internalized *P. aeruginosa*, down to the levels seen in CF cells." These results demonstrate that impaired ASMase activity in CF causes decreased bacterial uptake.

In Honor of

(Contributions listed were received from
March 1, 2008 to April 30, 2008)

CF Center Nurses
CF Friends Everywhere
Chelsa About
Adam Aliotti
Gianna Altano
Sadie Anderson
Jessica Arvidson
Haleigh Baker
Kyle Baker
Matt Baptiste
Robin Baptiste
Lucy Barnes
Allison Best
Rebecca Boyer
Brian Burks
Sean Campise
Anita Cass
Lauren Catron
Shaun Collins
David Cone
Nicholas Cook
Sara Jane Dickey
Sandra Donaldson
Dylan Dunn
Tess Dunn
Maxine Eggerth
Daniel Ellett
Alanah Fink
Jarod Fischer
Victoria Flamenco
Kathleen Flynn and Family
Jacob Fraker
Joseph Fraker
Emily Fredrick
Jessica Fredrick

"In Honor of" lists names of living persons in whose honor a donation has been made.

At your request we will send a special message to the recipient informing him/her of your contribution. Your donation not only recognizes your loved one's special occasion: it benefits children and adults with cystic fibrosis and their families as well.

Mail your contribution with the name, address, and the occasion for the person you are honoring to:
CFRI, 2672 Bayshore Parkway,
Suite 520, Mountain View, CA 94043.

Barbara Greenberg
Will Harbison
Kerry Harrison
Barbara Harwood
Erinn Hoyt
Bobbie Jensen
Ed Jensen
Lindsey Jensen Nijmeh
Michelle Jones
Alex Karwowski
Jeremy Kharrazi
Bill Kipp
Lori Kipp
Norma Kipp
Shae Kish
Bridget Klein
Santosh Krishnan
Cody Lawrence

Barbara Lenssen
Joseph Librers
Michael Livingston
Rose Logue Harting
Dr. and Mrs. Richard Marias
Larissa Marocco
Claire McCabe
Rachel McMullen
Rebecca McMullen
Carly Lee McReynolds
Nancy Melvin
Jonathan Miller
David Mischel
Fiona Mischel
Lucia Ogle
Billy Pelzl
Steven Peterson
Melissa Predny

Terri Price
Robyn Primack
Justin Raines
Briauna Red
Rebecca Roanhaus
Ann Robinson
Carl Robinson
Clare Robinson
Rob Robinson
Cortney Roeder
Andrew Sabatino
Katelyn Salmont
Rachel Silver
Joe Sinnaeve
Brian Smith
Matthew Spadia
Anabel Stenzel
Isa Stenzel Byrnes
Amy Stewart
Heidi Tegner
SiriVaeth-Dunn
Betty Vitousek
Mat Vitousek
Devin Wakefield
Scott Wakefield
Terri Walton
Clare Webster
Richard Whicker
Lauren Williams
Mr. and Mrs. Ralph Williams
Cynthia Witman
Emily Woods
Thelma Worthen
Dr. Hock Yeoh
Laura Zellmer

We regret a misspelling in our last newsletter: a donation was made in honor of Lindsey Nijmeh.

We were also able to show that the decreased cell death post *P. aeruginosa* infection in CF mice could be corrected by the addition of ASMase to the CF cells.

In CF, with decreased bacterial uptake and decreased bacterial killing, there is increased bacterial burden. The increase in the numbers of *P. aeruginosa* in the lungs could further stimulate the immune response and finally result in an overwhelming chronic infection.

In summary, understanding the mechanisms involved in the predilection for pseudomonas infection in CF and the emergence of a chronic infection and inflammation is critical to the development of new and improved therapeutics aimed at preventing or clearing infection and decreasing inflammation in CF airways.

Pediatric to Adult Healthcare (continued from page 3)

- IV's. What is your role? Does he/she want you to continue to go to appointments?
6. Talk with your health care providers about your child's wishes regarding your involvement in their care. Your adult child must be included in this discussion. If your child is over 18 (an adult), he/she needs to sign a statement regarding his/her wishes and send copies to all health care and insurance providers as well as the university health center if enrolled as a student. A healthcare directive should also be completed.
7. Find ways to communicate regularly and honestly. The changes that come with worsening health can be scary to everyone in the family.
8. Remember that this is your adult child's life to live as best as he/she can. Respect his/her choices.
9. Respect that you may feel the stress of chronic grief. You may not have the same emotional freedom that your friends with healthy adult children have. Take care of yourself too.
10. Join other parents of teens and young adults going through similar transitions at the CFRI conference on August 1, 2 & 3rd.



CFRI's Mission

Cystic Fibrosis Research, Inc. exists to fund research, to provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.

CFRI's Vision

As we work to find a cure for cystic fibrosis, CFRI envisions informing, engaging and empowering the CF community to help all who have this challenging disease attain the highest possible quality of life.

Get to know us:

www.cfri.org 650.404.9975

Cystic Fibrosis Research, Inc., • a 501(c) (3) non-profit organization, • Federal ID# 51-0169988

*Special Thanks to: **Genentech, Inc.**, maker of Pulmozyme® for their generous support of *CFRI News*.*

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