

# CFRI NEWS

*An Educational Community Contribution by CFRI*

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## The History of the Elizabeth Nash Memorial Fellowship Program

By Jonathan Widdicombe, Ph.D.



Jonathan Widdicombe, Ph.D.

After discussions with Bay Area CF researchers, Cystic Fibrosis Research, Inc. instituted a post-doctoral fellowship-training program in 2000. Liz Nash was one of the first recipients of this fellowship, and upon her death, the program was renamed the Elizabeth Nash Memorial Fellowship Program.

The Program has four fellows at any one time, with each fellowship lasting two years. Before the advent of the

Program, CFRI had awarded the bulk of its research funds to individual research projects. And though this form of funding still exists, a fellowship program has several advantages. First, the Program has a faculty of seventeen well-funded, nationally recognized researchers spread out between all major Bay Area universities and research institutes. Thus, fellows are assured of excellent working environments. Second, each fellow has two supervisors or mentors. The fellow thereby promotes collaborations among the faculty, and also has access to more techniques and experimental approaches. Third, regular fellowship meetings are held at which the fellows and their mentors provide the "critical mass" needed for

the effective exchange of ideas and the sharing of facilities and information. Finally, to get a fellow, a faculty member has to provide a research proposal for external review, with only the best proposals being funded. In fact, all proposals so far, even those not awarded a fellow, have been highly rated by the reviewers.

The first request for fellows was in the form of advertisements in *Science and Nature*. About 25 applications were received, from whom Elizabeth Nash and Tobias Jacob were selected.

Almost immediately, Elizabeth resigned her position due to health reasons, though she continued to serve CFRI as chair of the Research Advisory Committee. Her position was given to Britta Swanson. Tobias Jacob soon left for Penn State University, but was rapidly replaced by Grischa Chandy. After these initial hiccups, the program settled down with Britta Swanson, Christian Schwarzer, Jeremie Roux and Zhenyue Tong all completing their two-year fellowships. In the last year, three new fellows have joined the program. A full list of the fellows, their primary supervisors, and their present positions is given in Table 1 below.

*(Continued on page 9)*

**Table 1. Elizabeth Nash Memorial Fellowship Program (2000-2004)**

FELLOW	DATES	SUPERVISOR	UNIVERSITY	PRESENT POSITION
Elizabeth Nash, Ph.D.	2000	William Welch, Ph.D.	UC-SF	
Tobias Jacob, Ph.D.	2000	Terry Machen, Ph.D.	UC-B	Post-Doctoral, Penn State U
Grischa Chandy, Ph.D.	2000-2001	Terry Machen, Ph.D.	UC-B	Senior Research Scientist, Stanford University
Britta Swanson, Ph.D.	2000-2002	Jeanine Wiener-Kronish, M.D.	UC-SF	Assistant Professor, California State University SF
Kendra Rumbaugh, Ph.D.	2001	Jeanine Wiener-Kronish, M.D.	UC-SF	Post-Doctoral Research Texas Tech University
Christian Schwarzer, Ph.D.	2001-2003 <i>6 month extension</i>	Horst Fischer, Ph.D.	CHORI	Post-Doctoral UC Berkeley Current Research - CFRI
Zhenyue Tong, Ph.D.	2001-2003	George Caughey, M.D.	UC-SF	Post-Doctoral, Ohio
Jeremie Roux	2001-2003 <i>6 month extension</i>	Marybeth Howard, Ph.D.	UC-SF	Pre-Doctoral, UCSF Current Research - CFRI
Jeffery Wang, Ph.D.	2003-now	Paul Quinton, Ph.D.	UC-SD	Current Research - CFRI
Kwon-Yul Ryu, Ph.D.	2003-now	Ron Kopito, Ph.D.	Stanford	Current Research - CFRI
Yin Chen, Ph.D.	2003-now	Reen Wu, Ph.D.	UC-D	Current Research - CFRI

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## From the Executive Director

Examining messages within the currently popular "Lord of the Rings," I am struck by the power of *fellowship*. In the context of overcoming daunting challenge, this means more than just sharing time and space. It means committing energy you didn't know you had to a common cause, charting paths together through new territory in support of a worthy goal, and pooling resources to strengthen the efforts of the group.

CFRI is a community of fellowship. Despite the demands of personal and family health care in the world of CF, and in spite of fewer financial resources under difficult economic conditions, volunteers continue to find extra time and energy to move the organization forward. By serving on the organizing Conference Committee and helping the staff, volunteers made last July's Conference at the Sofitel in Redwood Shores a huge success. We thank them and the sponsors who made this occasion possible. Participants from fifteen states across the country attended this valuable three-day event.

The research presented by our own post-doctoral fellows and those widely recognized in the field of cystic fibrosis is leading to advances in CF clinical practice. Exciting new developments were also presented by Jeff Wine at the October Membership meeting. You can expect no less from the coming Educational Conference in 2004, given the dynamic slate of speakers on board.



*Carroll Jenkins,  
Executive Director*

Craig Burleigh Photography

We are enriching that August event by including those who cannot attend in person. In collaboration with Breathing Room, we will host a two-day Gallery of Art, which will feature works from across the country sent in by those with CF and their caregivers. I encourage you to read about it in this issue of the newsletter and invite you to join in!

The Retreat was another important opportunity for learning and sharing experiences in a safe environment. It was a time of "recharging batteries" to meet the challenge of living with this disease. The value of connecting with others was spoken to with one voice.

Thanks to our Tea Senders, our donors and to R.C. Bigelow, Inc., our Mothers' Day Tea raised over \$200,000 in 2003, enabling us to maintain our strong support of research. The Special Gifts campaign has also been successful and continues to bring in revenue. The CFRI Golf Tournament and other events sponsored by so many have made 2003 a year of growth for the organization. Many thanks to you all.

Finally, we are pleased to be working together with several CF organizations, including The United States Adult Cystic Fibrosis Association (USACFA), Breathing Room, The National Cystic Fibrosis Awareness Committee, The Reach for the Stars Foundation, the Heroes of Hope project, The Milan Foundation and other initiatives. By pooling our resources we move closer towards a goal of longer, healthier lives and a cure for cystic fibrosis. Please stay in touch.

Warmly,

*Carroll Jenkins*

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## CF: Living It, Researching It and Where We Are Now

By Jennifer Block Martin

*Presented by Paul Quinton, Ph.D.,  
Professor of Biomedical Sciences (Physiology)  
UCSD and University of California Riverside*

“I’m two years older than CF,” proclaimed Paul Quinton. Indeed, that’s true technically. The Texas native was born in 1944, but it wasn’t until 1946 that pathologist Dorothy Anderson named the disease she had been studying for a decade “cystic fibrosis.”

Unfortunately, this diagnosis didn’t catch up with Dr. Quinton until he was in college at the University of Texas. Growing up, his mother who would do anything to get her scrawny son to gain weight and even fashioned a mist tent out of bed sheets. After being wrongly diagnosed with chronic bronchitis, tuberculosis and then bronchiectasis of the upper lungs, Dr. Quinton came across a description of this new disease. His doctor said it sounded like what he had, except life expectancy was only eight or nine years. As a college student, Dr. Quinton didn’t know what to make of this discovery.

After a colleague suggested that being a physician would subject him to too many germs, Dr. Quinton decided to become a scientist. His mission was his own disease. Working at Rice University and then UCLA, with support from the National Institute of Health and CFRI, Dr. Quinton targeted the sweat gland as primary diagnostic tool for the disease. He discovered that chloride ions do not get through to the cells. As he says, “Making a discovery in science is the most exciting feeling!”

Dr. Quinton touched upon other developments in the fight against cystic fibrosis:

- In the past year, scientists have created a 3-D structure of the gene MBD-1, which is a portion of the molecule of CF. “This puts them in a good position for rational drug design,” he notes.
- In the last 4 to 5 years, high glucose screening has been more prevalent. He is excited about the drug-like compounds on the horizon.
- Dr. Quinton says, “Gene therapy is beginning to move forward after years on the back burner.” Transgene, a biopharmaceutical company, is having encouraging results with tgAAV, which carries the gene into the CF cells.
- Transplant operations are having a higher success rate.
- We know that inflammation does long-term damage to the lungs. Anti-inflammatory medications, such as ibuprofen are preserving lung function for longer periods of time with good effect.
- There are at least 2,000 people with CF over the age of 40, and maybe more who have not been counted.

Dr. Quinton says people need to be scientists and doctors themselves. Figure out the symptoms and work backwards. If you become sick, recreate scenarios so you’ll know what to avoid next time. He feels handshaking is a bad practice. “Be careful of people who are sick,” he says. “I’d move to the other end of the room. In Japan, people with colds wear masks out of courtesy for other people. I want to see this in our society.”

Dr. Quinton never expected to be here today. Since he was diagnosed with CF, he has only given himself 5-year plans. Yet his advice is “Live as though you’ll die tomorrow, but plan as though you’ll live forever.”

*Jennifer Block Martin, a writer, lives in San Francisco with her husband, Dave, who has cystic fibrosis. ■*



Paul Quinton, Ph.D.

Craig Burleigh Photography



## Special Thanks to Our Conference Sponsors for Their Generous Support!

CFRI’s Annual Educational Conference would not be possible without the generous donations of our sponsors. Because of them, CFRI is able to offer this valuable event at an affordable rate for our attendees.

The following sponsors contributed to our 16<sup>th</sup> Annual Educational Conference last July at Sofitel, Redwood Shores:

**Axcan Pharma, Inc.**

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**Sinus Pharmacy**

**The Reach for the Stars  
Foundation**

We are also thankful for all those individuals and corporations that donated prizes for our Raffle Drawings.

# Inhaled Glutathione as a Potential CF Therapy

By Kathleen Flynn

Craig Burleigh Photography



Clark Bishop, M.D.

*Speaker: Clark Bishop, M.D., Utah Valley Regional Medical Center, Provo, Utah, and Valerie Hudson, Ph.D., Professor of Political Science, Brigham Young University, Provo, Utah and mother of six children, three with CF*

Dr. Clark Bishop and Dr. Valerie Hudson began their presentation by running a video from NBC's Today show. The segment featured Dr. Hudson's foray into CF research after her son, John, now 6, was diagnosed with cystic fibrosis as a baby. In her desperation, she taught herself anatomy from her older son's high school anatomy textbook and began her long journey into the field of CF research. As the years passed, she became intrigued with the chemical glutathione and its role in the cell. After coming to believe that this chemical could make a difference in the health of her sons, Dr. Hudson eventually recruited Dr. Bishop to run a small, preliminary study using inhaled glutathione. Dr. Hudson presented their results.

Glutathione (GSH) is a tri-peptide, a very small protein, present throughout our bodies, but it appears in especially high concentrations in the epithelial lining fluid of the lungs. (Epithelial cells are the cells that line the inside of our lungs and they produce this fluid.) When the body has to deal with high levels of free radicals and oxidative stress, as is the case in CF lungs, the body provides higher levels of GSH to help it cope. GSH has several properties. It is a natural mucolytic. It helps regulate the immune response, as both an anti-inflammatory and as a cell-signaling molecule directing the white blood cells as to where and what to fight. It scavenges free radicals, and it is an anti-oxidant. Additionally, oxidized GSH protects proteins during stressful events in the lungs.

There is significant evidence of the importance of GSH in CF pathophysiology. At the 2000 CFRI Conference, you may have heard Dr. Rabin Tirouvanziam give an update on his GSH research. Dr. Bishop reported on a more recent study that showed that normal mice lung cells, when challenged with *Pseudomonas aeruginosa*, increase levels of epithelial lining fluid GSH six-fold to help fight the infection. By contrast, CF mice have significantly lower levels of a GSH response. This response is severely reduced in people with CF as well.

Dr. Bishop presented his small-scale, preliminary trial using inhaled glutathione. The GSH used was "pharmaceutical grade of 98.6 percent," it was buffered and diluted to minimize irritation, and it was tested and found free of bacterial and fungal products. He also relied on the results from seven other published human trials, which observed no significant adverse events when used. In his randomized, placebo-controlled, double blind, clinical trial of inhaled GSH, Dr. Bishop recruited 19 subjects. Ten used the inhaled GSH and nine used the placebo. The age range of the subjects was from six to eighteen, and the trial occurred during the summer months. Patients inhaled through a mask nebulizer approximately 66 milligrams per kilogram of their body weight of GSH mixed with sterile water, divided into four daily inhalations sessions, each three to four hours apart.



Valerie Hudson and Clark Bishop

The results of this clinical trial showed significant improvement in 11 out of 13 factors measured before and after use of GSH, including peak flow, overall improvement in health, and reduced cough. Dr. Bishop is the first to recognize the limitations of his trial (size is a significant factor), while drawing the following conclusions. GSH deficiency in epithelial lining fluid may play a major role in pathogenesis of CF, and GSH inhalation therapy appears to be effective for CF.

Dr. Bishop issued a clear caution to parents and adults with CF that further research still needs to be done before this can be considered a legitimate therapy for the CF community. Further research needs include a large, multi-centered clinical trial, the use of an FDA-approved product, and methods to increase convenience and control of administering the product. (Patients had to prepare their own solutions using capsules and sterile water, so doses were hand-prepared. This is time-consuming and dosages are not necessarily exact). Additionally, Dr. Bishop urged clarification of the route of delivery (oral vs. inhaled), dosage specifications, schedule of administration of the drug, patient selection, and other GSH augmentation tactics.

Dr. Bishop warned that this is an experimental therapy not approved by the Cystic Fibrosis Foundation. No long-term studies have been done to ensure safety and efficacy of GSH use. He further cautioned his audience that the CFF recommends *not* using this GSH inhalation therapy until further studies are done. Let's hope funding agencies and researchers are eager to pursue research into this promising potential therapy for our community. ■

# CF in the Classroom

By Jennifer Block Martin

*Presented by Linda Lenoir, R.N., district nurse for Palo Alto Unified School District, and Jeanne Kane, M.A., program coordinator and education specialist at Lucile Packard Children's Hospital*

School can be a stressful time for any child. But for one who requires medication or treatments during the day, has frequent absences due to hospitalizations, or even just needs a little extra time getting from classroom to classroom, school can be a daunting experience. Thankfully there are programs available to ensure that children and parents get the services they need.

Presenters Jeanne Kane and Linda Lenoir both implored parents to be advocate #1 for their children. They also emphasized the need for parents to find an ally in their school, whether it's the school nurse or a counselor who knows how the district works.

Ms. Kane is the coordinator at Lucile Packard Children's Hospital of a program called H.E.A.L., or Hospital Educational Advocacy Liaisons, which aims to smooth the often rocky transition from hospital to school. She also gives presentations about cystic fibrosis to classrooms, so other children can become your child's advocate, too.

Ms. Kane explained the labyrinth of state and federal laws governing who qualifies for special help, including the Individuals with Disabilities Education Act of 1975 (IDEA), the Individualized Education Plan (IEP), and the Rehabilitation Act of 1973 (also called the 504 plan).

The 504 plan prohibits discrimination against qualified individuals. All children with CF are qualified for 504 eligibility, but it may not be enough to meet their needs. The next step is an IEP. The IEP is both a program/process and a meeting, resulting in legal document. It is based on needs, not cost and it is reviewed every year.

Ms. Lenoir noted that it's better to have the IEP in place *before* you have a problem. Then you don't have to worry. For example, it may take a long time to find teachers to do home visits. If you have this process set up ahead of time, your child will benefit. Come to your meeting with a list of questions and needs. Communication with teachers is essential; they should inform you of what's going on in the classroom. Also, ask your child what is hard during the day and what would make things easier. Is it easier for your child to carry enzymes with him or her instead of going to the nurse's office? Will your child be able to eat a snack or drink water at any time? Will he or she be allowed to go to the bathroom at any time without asking permission? Can he or she start school later if morning treatments are necessary?

Kane shared some tips for parents who are in the process of getting an IEP:

- Secure appropriate services
- The school is not the enemy—make them a partner in the process  
Enlist help, even from a neutral third party if necessary
- “Appropriate Education” doesn't mean “best” but what will meet the child's needs
- Focus on the big issues

Make sure the right people—teachers, aides, nurses, etc.—are at your meeting. Then, with a personal phone call, ensure that all of the teachers—including art, physical education and other subjects—understand the importance of the IEP meeting results.

Ms. Lenoir stressed that schools need new doctors' orders and paperwork every year, and these need to be presented to the school before the first day.

*Jennifer Block Martin, a writer, lives in San Francisco with her husband, Dave, who has cystic fibrosis. ■*

Craig Burreigh Photography



Jeanne Kane

Linda LeNoir



Craig Burreigh Photography

## Milestones

### *Birthdays:*

**Joanne Schum,**  
40 on July 18, 2003  
**Mary Lou Allocco,**  
49 on April 3, 2003  
**Catharine Martinet,**  
42 on June 3, 2003  
**Kasey Schumacher,**  
7 on August 5, 2003  
**Beth Sufian,**  
38 on August 13, 2003  
**Kathy Schaal,**  
40 January 23, 2004  
**Elisa Peoples,**  
22 on November 27, 2003  
**Bingo Wright,**  
39 years on December 21, 2003  
**Ricky Whicker,**  
8 on November 26, 2003  
**Pat Flynn,**  
December 3, 2003  
**Tracy Miley,**  
37 on September 10, 2003  
**Anabel Stenzel,**  
32 on January 8, 2004  
**Isabel Stenzel-Byrnes,**  
32 on January 8, 2004

### *Graduation:*

**Joey Yerves,**  
High School, June 13, 2003

### *Weddings:*

**Eric Wood and Kathy Schaal**  
January 25, 2003

### *Wedding Anniversary:*

**Mary Lou and Edward Allocco**  
25 years, June 24, 2003

**John and Jamie Smith**  
10 years, November 6, 2003

**Bingo and Gail Wright**  
19 years, September 29, 2003

**Isa and Andrew Byrnes**  
5 years, June 27, 2003

**Dave and Jennifer Block Martin**  
5 years, October 10, 2003

### *Transplant Anniversary:*

**Joanne Schum,** 6 years  
on September 12, 2003  
**Mary Lou Allocco,** 2 years  
on March 3, 2003

**Melissa Reta,** 3 years  
on May 24, 2003

**Nahara Mau,** 3 years  
on November 6, 2003

### *Bar Mitzvah:*

**Jeremy Kharrazi,**  
13 years old in August 2003

## NEW Program Celebrates Hope for People Living With Cystic Fibrosis

A panel convened and sponsored by Genentech, Inc. recently announced a new recognition program designed to honor people with cystic fibrosis who give hope to others. HEROES OF HOPE™ LIVING WITH CF, brought to the public by Genentech, will celebrate individuals with CF who inspire their community by demonstrating courage, determination, and a positive attitude while managing their health everyday.

### THE HEROES OF HOPE LIVING WITH CF MISSION

The mission of HEROES OF HOPE LIVING WITH CF is to recognize the contributions of inspirational people affected by cystic fibrosis, a grueling genetic disease that affects 30,000 people in the United States. In cystic fibrosis, a defective gene causes the body to produce an abnormally thick and sticky mucus that clogs the lungs and obstructs the pancreas, making breathing and food absorption difficult. According to the CF Foundation's National Patient Registry, the median age of survival for a person with the disease is 33.4 years.

"Today there is a whole new generation of people with CF, and HEROES OF HOPE LIVING WITH CF is a wonderful opportunity to celebrate the lives of those coping well with the disease," explains Ana Stenzel, a co-chair of the program who has CF and is a double-lung transplant recipient.

"As anyone with CF knows, living with the disease on a daily basis can be very difficult," said Isa Stenzel-Byrnes, co-chair and twin sister to Ana who also has CF. "To the person with CF, leading an active life can be a burden or joy. The purpose of this program is to embrace our active lives in the face of this burden and offer hope to the CF community."

### HOW THE PROGRAM WORKS

Beginning in November, nomination forms have been sent to Cystic Fibrosis Care Centers across the nation. Each month, an independent panel comprised of physicians, nurses, advocates, and people living with CF will select a



HEROES OF HOPE LIVING WITH CF award recipient based on established criteria including:

- having a positive attitude in living life fully and pursuing their dreams
- managing their health maintenance regimen on a daily basis
- showing strength and determination in confronting the challenges of living with cystic fibrosis
- being role models by providing a service to their community
- demonstrating a sense of achievement, skills, or special talents.

### WHY WAS HEROES OF HOPE LIVING WITH CF CREATED?

"Sometimes people affected with CF can become discouraged by having to follow the many treatment therapies for the disease, which require significant time and discipline," said Randall Young, Jr., MD, professor of medicine and director, Division of Pulmonary, Allergy and Critical Care Medicine at the University of Alabama at Birmingham Medical Center and a Heroes of Hope Panel member. "However, by managing their health maintenance regimen on a daily basis, people with CF can live longer, healthier lives. The HEROES OF HOPE LIVING WITH CF program applauds those individuals who employ hard work and dedication to proactively manage their health."

### RECOGNITION OF HEROES OF HOPE RECIPIENTS

Recipients of the HEROES OF HOPE LIVING WITH CF award will be recognized on the Pulmozyme website in a section entitled "Heroes of Hope Living with CF" located at [www.pulmozyme.com](http://www.pulmozyme.com). Each winner will also receive a certificate of recognition, a T-shirt, and a commemorative gift. Nomination forms can be obtained from CF Centers nationwide or downloaded online by going to [www.pulmozyme.com](http://www.pulmozyme.com) and clicking on HEROES OF HOPE™ LIVING WITH CF. ■

# 17<sup>th</sup> Annual CFRI Educational Conference

## *One Day at a Time: Thriving with Cystic Fibrosis*

**August 6-8, 2004 Sofitel Hotel, Redwood City, California**

This year's CFRI conference committee has set the stage for a most exciting event this summer. Topics will include advances in clinical care, stem cell and basic research, and respiratory therapy. We will also meet a young woman with CF who will share some of the challenges she has faced – Lo Detrich.

This year's speakers will include:

**Margaret Hodson, M.D.**, of the Department of Cystic Fibrosis at the Royal Brompton Hospital in London, England.

**Richard Mollard, M.D.**, of the National Stem Cell Centre at Monash University in Melbourne, Australia.

**Andre' Cantin, M.D.**, of the Department of Medicine at the Universite' de Sherbrooke in Quebec, Canada.

**John Saito, M.D.**, of the Department of Pulmonology at University of North Carolina in Chapel Hill, North Carolina.

**Dennis Nielson, M.D., Ph.D.**, Chief Pediatric Pulmonologist at University of California San Francisco

**Jonathan Widdicombe, Ph.D.**, of the University of Davis, California, and of our CFRI Post Doctoral Fellowship.

**Kristin Shelton, RRT**, of Lucile Packard Children's Hospital at Stanford in Palo Alto, California.

**Lo Detrich**, of the book "Spirit of Lo," from Tulsa, Oklahoma.

A discussion panel will include the aforementioned doctors. A second panel will include a group of teens and adults with cystic fibrosis. Support groups will be scheduled to provide the time to share thoughts and experiences with others with CF and their extended families. A memorial service is scheduled to honor those who were an important part of our lives.

There will be an Art Gallery – not just any art gallery, but a collection of art expressions, which are a window into the lives of those with cystic fibrosis from the CF community across the country. Constructed in partnership with Breathing Room, this gallery will feature many aspects of the visual arts. Further details are on page 12. All members of the CF community are invited to participate. In connection with the gallery we will feature a speaker who will discuss the topic of art and healing.

CFRI is not alone in this important event. We are in collaboration with United States Adult Cystic Fibrosis Association (USACFA) and Breathing Room, and have the support of National Cystic Fibrosis Awareness Committee (NCFAC), the Reach for the Stars Foundation and others. Together we raise the global awareness of this disease with the hope of finding a cure and improving the quality of life for those who face the challenge of cystic fibrosis.

Scholarships are available to offset registration costs. Those with CF who would like to attend should contact our office regarding our medical guidelines. All are encouraged to respond to the "Call for Art" – deadline: May 1, 2004.

*Make your reservations early* with the Sofitel Hotel, Redwood City, CA @ 650-598-9000 and mention "CFRI Educational Conference" for our outstanding group rate of \$89 per night.

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## Reverend Alice Parsons Zulli: CF and Life Adjustments – Coping With What Comes

By Siri Vaeth-Dunn

The Reverend Alice Parsons Zulli shared strategies for improving one's coping skills in the face of a life threatening illness. Rev. Zulli, an Ordained Minister with a specialty in Clinical Thanatology (the field of death, dying and bereavement), is also Chaplain Associate and Director of Bereavement Support and Services at Glendale Adventist Medical Center, and co-founder and Program Director of The Center for Grief and Loss for Children. She shared her wealth of clinical experience, and provided advice and specific tasks to empower conference participants to cope with the challenges of cystic fibrosis.



*Reverend Alice Parsons Zulli*

Rev. Zulli teaches and lectures on death and healthy reconciliation after loss. Her presentation addressed coping with loss, not only the loss of loved ones, but also the loss of hopes and dreams that occurs with the diagnosis of cystic fibrosis. The diagnosis of a life threatening illness constitutes a disruption of our “assumptive world,” i.e. our world as we expect it to be. Rev. Zulli outlined the healthy process of coping with loss, in which individuals grieve each loss, then accommodate the loss, and ultimately move back into their assumptive world.

Rev. Zulli stressed that a key challenge for those dealing with a life-threatening illness is to empower themselves to better deal with whatever comes. It is crucial to talk about how to live each moment as productively and as joyfully as possible no matter the circumstance. The experience of a life-threatening illness is one of the most difficult experiences for individuals and families, which leaves a life long mark. She noted that “attitude is everything.” The healthy expression of feelings is critically important.

When confronted with illness or loss, Rev. Zulli stressed the importance of living in the present. Empowerment and coping can only occur if we stop holding on to the past and move in a “forward trajectory” through phases of coping. Post diagnosis, individuals may experience several phases which include the acute, chronic, and terminal phases. Rev. Zulli outlined “tasks” for each phase which increase the ability of individuals to cope.

The acute phase is experienced immediately after the crisis of diagnosis. In the chronic phase, individuals may be struggling with the disease and its treatment. There are often illness-related crises, including exacerbations and hospitalizations. In the terminal phase, the disease has progressed to point where death is likely. Rev. Zulli stressed that “until you're dead, you're very much alive,” and that some of the most precious moments can come at the end of life. Key tasks include managing stress and coping, preserving self-concept, and ventilating feelings and fears. Most challenging is to find meaning in life and death.

Rev. Zulli described four major tasks that exist with any experience of major illness. First is the need to respond to the physical facts related to diagnosis, medications, or new regimens. Next, individuals must take steps to cope with the reality— one day at a time, one hour at a time, one moment at a time. Very importantly, individuals must preserve self-concept and relationships. Finally, individuals must deal with the affective and spiritual issues created or reactivated during the illness. One should constantly reexamine one's world view.

Rev. Zulli emphasized that avoidance, resistance and fear are common responses to a life-threatening illness, but these responses are painful, isolating, and inhibit the healing process. It is important to keep communication open. Life threatening illness affects the lives of all members of the family, as well as the larger community of friends. Healing occurs by moving towards others in a positive trajectory. This will expand an individual's self concept, and empower him or her to cope with current and future challenges.

Rev. Zulli encouraged everyone to think about oysters as a metaphor for coping with the hardships of cystic fibrosis. As she described it, oysters are one of nature's most wonderful creations. When a grain of sand enters the shell, they do not try to eject this irritant. Rather, they embrace it, surround and coat it with their very essence. The oyster's ability “to wrap beauty around trouble” results in a pearl. Coping with a disease challenges our past assumptions and our current world view. Rev. Zulli encouraged everyone to lean into their grief, lean into their illness, and into their lives. She encouraged all to wrap beauty around trouble, and to make our own pearls. ■

# Relationship Between Psychosocial Issues and Nutritional Status

Presented by Rebecca Bathon, M.S.W., Clinical Social Worker in Program Development, Barnes-Jewish Hospital, Washington University, St. Louis

One of the things we know about cystic fibrosis is that good nutrition is very important for survival. Rebecca Bathon has studied the effects of psychosocial issues on CF patients' nutritional status, including biological, psychological, spiritual and social matters, and she shared some of her findings at the CFRI Conference.

During the period of May 1, 2001 to April 30, 2002, Ms. Bathon and her team studied 115 patients ranging in age from 18 to 52 years who were living in both urban and rural environments. Most were diagnosed before age 1, 57% were male, 86% were pancreatic insufficient, 77% were hospitalized 0 to 1 times yearly, 18% had had transplants, 11% had cystic fibrosis-related diabetes, and 4% had enteral/tube feedings.

Of the total, 19 people were considered underweight, with a body mass index (BMI) of less than 18.5. BMI is a tool for indicating weight status in adults. (BMI is not normally used to chart children.) For adults more than 20 years old, a BMI of 18.5 to 24.9 is considered normal. The National Center for Chronic Disease Prevention and Health Promotion has a BMI calculator at <http://www.cdc.gov/nccdphp/dnpa/bmi/calc-bmi.htm>

Here is the formula:

$$\text{BMI} = \left( \frac{\text{Weight in Pounds}}{(\text{Height in inches}) \times (\text{Height in inches})} \right) \times 703$$

It was determined that patients with a lower BMI had poorer lung function and 2 or more hospitalizations per year. The majority of underweight subjects were female, pancreatic insufficient, transplant recipient, and on Social Security Assistance. Also, 68% were single, and 58% had divorced parents.

Ms. Bathon's team's recommendations:

- Ensure collaborative efforts within the medical support team
- Educate the patient and family about healthy weight and encourage their active role in maintaining good nutrition
- Make a comprehensive psycho-social evaluation
- Encourage strong peer support
- Dispel myths of body image for women

In the discussion that followed the presentation, one parent expressed her happy surprise to learn that Barnes-Jewish Hospital provided parents with such an attentive team of professionals. She wished her dietitian would talk more with her family about calories, nutrition and weight gain, instead of just telling her that her child needs to eat more. ■

## Elizabeth Nash Fellowship Program (continued from page 1)

The research funded has been diverse. Proposals have included: studies of ion transport across small airways, characterization of a newly discovered mucin that may contribute to CF pathology, attempts to find small molecules that promote trafficking of mutant CFTR through the cells, the effect of *Pseudomonas aeruginosa* on signaling pathways in airway epithelial cells, the role of CFTR in intracellular organelles, regulation of the absorption of water across airway epithelium, studies on the mechanism of acid secretion into the airways, and methods to determine the degree of binding of *Pseudomonas* to the epithelium. Generally, it takes about two years between the start of a research project and the appearance of publications. So, it is early yet to assess the success of the Fellowship Program in these terms. However, a number of articles in respected journals have already been produced as shown at the right sidebar.

In the future, the Fellowship Program will be modified to allow a greater role for the CFRI Research Advisory Committee in its administration. The meeting format will be altered so as

(Continued on right sidebar)

## Elizabeth Nash Fellowship Program

(continued from bottom left)

to allow greater interaction with the CFRI general membership. Remaining meetings for 2004 are as follows: April 27 (Oakland), July 13 (Stanford), August 7 (Redwood Shores), and October 26 (Oakland). And, finally, should good proposals be forthcoming, it is hoped that "translational" research can be funded – work aimed at applying basic research findings to clinical treatment.

## Publications

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5. Machen, T. E., G. Chandy, M. Wu, M. Grabe and H. P. Moore. Cystic fibrosis transmembrane conductance regulator and H<sup>+</sup> permeability in regulation of Golgi pH. *Jop* 2:229-236., 2001.
4. Jacob, T., R. J. Lee, J. N. Engel and T. E. Machen. Modulation of cytosolic Ca<sup>2+</sup> concentration in airway epithelial cells by *Pseudomonas aeruginosa*. *Infect Immun* 70:6399-6408., 2002.
2. Frank, J., J. Roux, H. Kawakatsu, G. Su, A. Dagenais, Y. Berthiaume, M. Howard, C. M. Canessa, X. Fang, D. Sheppard, M. A. Matthay and J. F. Pittet. TGF-beta 1 decreases expression of the epithelial sodium channel alpha ENaC and alveolar epithelial vectorial sodium and fluid transport via an ERK 1/2-dependent mechanism. *J. Biol. Chem.* 20:20, 2003.
3. Howard, M., H. Fischer, J. Roux, B. C. Santos, S. R. Gullans, P. H. Yancey and W. J. Welch. Mammalian osmolytes and S-nitrosoglutathione promote ΔF508 cystic fibrosis transmembrane conductance regulator (CFTR) protein maturation and function. *J. Biol. Chem.* 278:35159-35167., 2003.
6. Swanson, B., R. Savel, F. Szoka, T. Sawa and J. Wiener-Kronish. Development of a high throughput *Pseudomonas aeruginosa* epithelial cell adhesion assay. *J Microbiol Methods* 52:361-366., 2003.
7. Verghese, G. M., Z. Y. Tong, V. J. Bhagwandin and G. H. Caughey. Mouse Prostate\* Gene Structure, Promoter Analysis, and Restricted Expression in Lung and Kidney. *Am. J. Respir. Cell Mol. Biol.* 4:4, 2003. ■

# 2003 CFRI

## Comments From A Conference Attendee

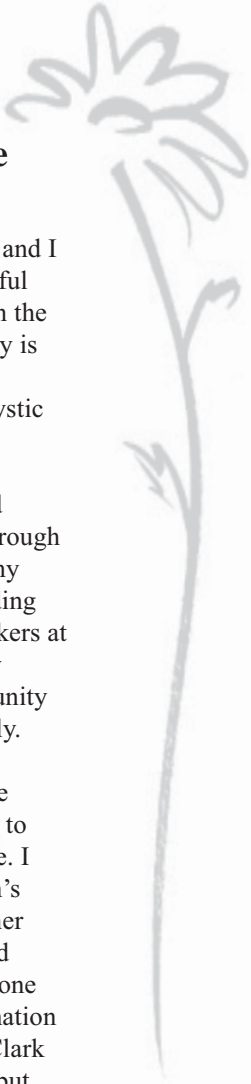
By Karin Shinpaugh

My name is Karin Shinpaugh and I am the mother of two wonderful children. Austin is 13 and is in the 7th grade. My daughter Ashley is 11 and she is in the 6th grade. Ashley was diagnosed with cystic fibrosis at two.

For several years I have heard about the CFRI conference through my web group. Members of my group would talk about attending and about the wonderful speakers at the conferences. This year my husband and I had the opportunity to attend the conference in July.

Valerie Hudson was one of the primary reasons that I wanted to come to this year's conference. I had read her article in Woman's Day Magazine and had seen her interview on NBC. I have read about the research on glutathione on my web group. The information that Valerie Hudson and Dr. Clark Bishop gave was interesting, but the testimonies of the people who are now using GSH were inspiring.

The CFRI conference was outstanding. It was very professional and well organized. The speakers were knowledgeable and interesting. The people we met were warm and dear. I have to admit that I am very jealous that you have such a wonderful support system in California. I only wish that we had a support group like the CFRI in Texas. Coming from Dallas to the CFRI conference was well worth the trip. Knowledge is power and I plan on learning as much as possible. Attending the conference was a wonderful experience. I want to thank you for making us feel so welcome. I look forward to seeing you next year.



# Annual Conference



## Note from a Parent

By Sandy Schumacher

I just returned from your annual educational conference and had to sit down to write you this thank you note. CFRI did an awesome job! The speakers were excellent and the topics were all presented positively. This set the tone for a very upbeat and informative conference. It was nice to see the familiar faces and meet new ones too. Not to mention the beautiful surroundings. Everything was fantastic.

Great job, and I'm looking forward to next year's conference already! Thank you for getting the information we so value.





## Mothers' Day Tea 2004!

\_\_\_ *Yes, I would like to send Tea invitations.*  
Please send me \_\_\_ (number of invitations)

**Your Name** \_\_\_\_\_  
(please PRINT)

**Telephone number (area code)** \_\_\_\_\_

**PO Box/Street Address** \_\_\_\_\_

**City/State/Zip** \_\_\_\_\_

**Email Address** \_\_\_\_\_

**Relationship to CF** \_\_\_\_\_




# Mothers' Day Tea

Our major fundraiser of the year is just around the corner. We provide you with the invitation and envelope, literature on CF, and a teabag of delicious Blueberry Harvest Tea. You then send the invitation to family and friends and join us all – across the country – for a cup of tea together. When donors read our literature and learn about CF, they can mail us a contribution in envelopes that are included with the invitation. It's that easy.

Your support enables us to fund important research and get new information to those with cystic fibrosis and their families.

This year, artist Sally Robertson has donated a beautiful watercolor entitled "Roses and Teacup" for our invitation, and R.C. Bigelow has generously supplied us with their newest edition of natural herbal tea.

**NEW THIS YEAR:** Send in your order coupon for at least 10 invitations by March 22<sup>nd</sup> if you would like to be eligible for the raffle drawing for a **beautiful new teapot!** It is a fitting acknowledgement of the great job you do as a Tea Sender for CFRI. Just clip this order form and send it to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043. You can also call your order in: 650-404-9975, or email us at [cfri@cfri.org](mailto:cfri@cfri.org). **THANK YOU!** 

**Note:** the March 22<sup>nd</sup> deadline is for the raffle only. We will still be accepting MDT coupons for sending invitations after March 22<sup>nd</sup>.

## You Don't Have to be "An Artist!"



### We Want You!

Do you enjoy creating through art? Do you have an experience of living with CF that you wish to express through your art? Do you draw/paint/sculpt/sew/etch or photograph? Then we are looking for you! CFRI and Breathing Room have joined in collaboration to hold a very special art exhibit at the 2004 CFRI educational conference. The title of the exhibit will be "One Day at a Time: Living with Cystic Fibrosis" and will feature artwork by adults and children with CF, family members, friends and caregivers.

### What Kind of Art?

We are looking for artwork in various media including: Pen and Ink, Charcoal, Pastel (oil and soft), Paint (watercolor, acrylic or oil), Collage/paper mosaic, Textile art, Photography, Etching, Ceramic, Mosaic, Polymer Clay, and Glass. We are very excited to view your work and know that the selection process will be difficult. Remember that we will have limited space so not all entries will be able to be exhibited. We will select entries to give as broad a range of experiences as possible about living with CF from the perspective of one who has it as well as those that live with, care for and know people with CF.

### Who Can Apply?

All artwork selected will be exhibited August 6-8, with a special reception the evening of August 6, 2004 at the Sofitel Hotel, in Redwood Shores, CA. We have four categories for entry:

- A:** Children with CF, their siblings and friends (under the age of 18)
- B:** Adults with CF (18 and older)
- C:** Family members, significant others and friends (18 and older)
- D:** People who are caregivers, medical practitioners, and counselors.



### Deadline

All Entries Must be postmarked by May 1, 2004. For an application, please see [www.thebreathingroom.org/st/st\\_mc01\\_artapp](http://www.thebreathingroom.org/st/st_mc01_artapp) or call Catharine Martinet at: 818-556-3970, or e-mail [cmartinet@excite.com](mailto:cmartinet@excite.com) ■

# Space Odyssey: Live Long and Prosper

By Isa Stenzel-Byrnes & Jessica Martens

The 2003 Cystic Fibrosis Teen and Adult Day Retreat was held at Vallombrosa Center in Menlo Park, California, August 4<sup>th</sup> to 8<sup>th</sup>. Thirty-eight individuals participated in the retreat in addition to 14 visitors. Last year, the retreat theme was “Space Odyssey” and our motto was appropriately “Live Long and Prosper.” Theme activities included a “Pod” race, “Moon Walk” and “Planet Hop” relay races, parachute drop, “Cyber Cafe” and actual stargazing. We were privileged to have excellent speakers, Cindy Lenssen Broshi and Mary Lee Levis, who spoke about their experiences with individuals with CF and alternative health care. The retreat also hosted Anna Simos, CDE, a diabetic educator from Stanford Hospital, who shared vital details of managing diabetes. Andrea Thronson came for the third year in a row to teach yoga to the group. The food and service was exceptional at Vallombrosa, and Costco Redwood City and Belmont Baskin Robbins donated some snacks.



2003 Retreat Attendees

Besides the practical aspects of the event, it is difficult to put into words the essence of CF Retreat. This is an ultimate coming-of-age experience for any youth with cystic fibrosis. Coming to CF Retreat offers that chance to be normal among peers who also do treatments, take enzymes and cough a lot. The focus is on providing activities that boost self-esteem, incorporate CF into one’s identity, and validate the interruptions that CF makes in school, relationships, and career pursuits. CF Retreat allows young people to build friendships with peers with CF who truly understand what the other is going through. People with CF are living longer and healthier lives, and retreat is a place where young people can meet role models who give guidance and tips on living well with CF. Retreat is a sacred place where one leaves self-consciousness, abhorrence, and denial of the disease in the outside world and enters a place of acceptance and personal growth. It allows teens and young adults to come out of their shells and experiment with personality types that they wouldn’t otherwise have a chance to explore with in the risk-filled outside world. Retreat is a safe haven to talk about how CF affects one’s future, death, sex, relationships and other taboo topics that may not always be discussed in the family or medical setting.

Most importantly at retreat, we all learn how to express ourselves deeply and openly, whether it’s by creating art, sharing in rap sessions, laughing so hard our stomachs hurt or by crying heavy tears over the losses we have experienced. The highlights of retreat are not always discovered in the most obvious of places, like during large group rap sessions, or during educational talks or during other formal activities. The most precious moments are during a small gathering of friends, perhaps during a meal or during rest time as people sit on the lawn under the trees that provide a sanctuary for intimate connections among friends. These moments of laughter and closeness create and proliferate lifelong friendships that make life worth living and provide precious companionship during the roller coaster ride of living with CF.

This year’s CF Teen and Adult Retreat is scheduled for August 1 to 6, 2004. We strongly encourage those with CF who are 15 years and older to attend. Cross infection rules apply, and the retreat is planned with the strictest sanitation and safety policies in mind. All participants with CF need to check with the office prior to registration to receive our cross-infection guidelines, and forms requiring a physician’s signature.

The retreat is also open to parents, siblings and other relatives, friends of people with CF, and significant others. One cousin of a CF teen, Heather Tarvin, has come from Massachusetts each year to retreat. She states, “ I go to retreat for many reasons. In the beginning it was to spend time with my cousin. Since then, I have met so many wonderful people and have such an amazing time that I can’t wait to go back. The week is always full of relaxation and a time to reflect. Many of the things CFers think of as “problems” most typical people deal with too. People with CF just have a unique way of looking at it! Basically, Retreat is a way to better understand what your family member is going through. By understanding them better you know how to be more helpful and supportive. It also teaches you a lot about the disease, lessons in life and gives you a unique view of living life to the fullest!” ■

# University of California, Davis Internship

By Michelle Jones

People with cystic fibrosis have always been pushing the boundaries. From carrying an Olympic torch to just surviving as students in college, we have been accomplishing what seemed impossible when we were diagnosed. Today many people with CF are only limited by their dreams. I am one example.

I was the first person with cystic fibrosis ever to attend the UC Davis Young Scholars Program (YSP). YSP is a six week-long summer program for 40 high school sophomores and juniors. The students are introduced to many scientific perspectives in a two-week lecture series, as they intern with a current research project on campus. They live in the dorms and experience college life. On Saturdays there are trips to help students relax. These included a trip to Tahoe research labs, Bodega Bay research labs, an overnight camping trip and climb to the summit of Mt. Lassen, a trip to the Monterey Bay Aquarium and Santa Cruz Beach Boardwalk, and finally a trip to San Francisco and Alcatraz.

This all sounds great, but with CF, what does it entail? After being accepted off the waiting list and having reality sink in, I began to have second thoughts. Where would I do my treatments? Would I end up getting sick? When everyone went to climb Mt. Lassen would I be the only one who didn't make it to the top? Would people notice I was different?

To answer the first question of apprehension, I was given a second room. This room was really a storage closet, but it offered me privacy for doing my treatments. No one knew I had this second room. This made things difficult. I would try to sneak in and out of it without people seeing because like all people with CF, I wanted to be perceived as "normal" for these six weeks. I felt awkward sneaking around, but no one noticed. I guess if I had told people my situation they would have understood, making my life a little easier, but I didn't.

I never got sick during the entire six-week period. I stayed on top of my medicines and did what I needed to do. This good health was made evident as I climbed to the snow-covered peak of Mt. Lassen ahead of many "normal" people who were in the program. I remember being up there and never thinking twice about the fact that I made it. I suppose I knew I would make it - there was no reason not to. I only limit myself by my dreams.

I ended up being interned with a great research project. The lab I was working in was using nematodes to explore the concept of aging and how aging could be postponed and lifetime expanded. I monitored wild type and mutated nematodes' movement on grids under the microscope. It was interesting and gave me an understanding of the tedious quality of research. It is far different from what you do in high school.

Socially I fit in at UC Davis. I made a lot of friends that I'm still in touch with. I never did tell them about CF, but I think that was all right. They didn't need to know about CF to know who I was. They didn't need it to judge me for better or worse. I know myself as me, not as "the girl with CF." Although CF is a big part of my life, it is not the definition of who I am. I learned a lot while I was gone, but most of all I learned that I am something greater than a label. I can do anything that I dream of as can anyone who has a heart to follow. ■

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## Living Well With Cystic Fibrosis Self-Management Classes

By Isabel Stenzel Byrnes and Ann Robinson

Since raising a child with cystic fibrosis is challenging in many ways, the Family Centered Care Program, the Cystic Fibrosis Center and the CF Parent Advisory Committee at Lucile Salter Packard Children's Hospital at Stanford offered a parent education workshop to address these challenges. The curriculum was written by many people including nurses, a social worker, adults with CF and parents of CF children. It was offered in two four-hour Saturday classes this fall. The curriculum was adapted from "Living A Healthy Life with Chronic Conditions," written by Kate Lorig, RN, DrPH.

Eleven families came together with one experience in common – they were parents of a child or children with cystic fibrosis. The goal of the workshop was to help parents better understand the impact of cystic fibrosis on our families and to better manage the disease. The goal was achieved by an emphasis on self-management, or the ability to feel confident in one's ability to solve problems. Tools that were used including building self-efficacy, mastering skills, and learning by modeling other parents.

Parents were provided with a place where they could feel safe and raise concerns, thoughts, and feelings that they had about any aspect of their child's illness as it affected their ill and healthy children, themselves and their entire family. They were also provided with specific information regarding the management of their child's illness because parents are the primary caretakers for their children. The workshop focused on three main areas: managing and providing medical care for the CF child, managing normal family life, and managing the often turbulent emotions that accompany taking care of a child with cystic fibrosis.

Isabel Stenzel Byrnes, MSW, MPH, an adult with CF and Ann Robinson, MA, mother of an adult with CF, co-taught the workshop. Joann Asano, LCSW, from the CF Center at Stanford, recruited the families and gained hospital-wide support. Lunches both days were provided by Chiron and Solvay Pharmaceuticals, the makers of TOBI © and Creon ©, respectively. The discussions included the following

*(Continued on page 16)*

## Antibiotic Treatment of Lung Disease in CF

By Lori Lindmeier



Craig Burleigh Photography

Lisa Saiman, M.D.

Lisa Saiman, Professor of Clinical Pediatrics at Columbia University and Attending Professor of Pediatrics at the Children's Hospital of New York, shared an informative presentation on the use of antibiotics for the treatment of lung infections in cystic fibrosis. After twenty years of clinical research experience in this field, she is an authority on multiple drug treatments of infection organisms in CF.

Dr. Saiman opened her talk with an introduction to the general principals of clinical trials, including the framing of an important clinical question for a study, the ethics, selecting the type, size and scope of a study, designing it, enrolling subjects, carrying it out and the outcomes and what they mean. She used this to segue into presenting some results from her own clinical trials with CF patients.

Dr. Saiman focused on examining the treatment of CF lung disease using two or more antibiotics in tandem to improve FEV1 and reduce *Pseudomonas aeruginosa* lung infections. In CF, antibiotics are used to treat pulmonary exacerbations, chronic suppression and early eradication of *P. aeruginosa*, and prophylaxis (true primary prevention). Antibiotic use for early eradication of *P. aeruginosa* has been a controversial topic. The idea to treat it

aggressively at the first acquisition has long caused discord between European and North American researchers. In the late 70s and early 80s, researchers questioned whether *P. aeruginosa* colonization was serious enough to warrant the use of routine antibiotics, risking earlier drug resistance. Much has been learned about the nature of *P. aeruginosa* and its ability to mutate in the lungs making it more difficult to control and impossible to eradicate. However, controversy about treatment continues.

Dr. Saiman noted that antibiotics can also be paired in fighting *P. aeruginosa* infections. One such combination is IV Tobramycin and Ceftazadine. (For milder exacerbations, an oral quinolone (Ciprofloxacin) might often be used with oral Azithromycin.)

Dr. Saiman referred to a recent study comparing Meropenem/Tobramycin with Ceftazadime/Tobramycin, to see if there was improvement in FEV1 and if there would be a reduction of *P. aeruginosa*. Although both groups experienced reduced *Pseudomonas* counts, it would appear that after seven days of the trial, those patients using Meropenem had improved their FEV1 by 15%, leading to overall better lung function in the long run.

A new option in the IV combination treatment for *P. aeruginosa* exacerbations is the combination of Azithromycin (Zithromax) and Tobramycin. An already licensed drug, Zithromax is well absorbed, has a long half-life (which means concentrations within the lung or host inflammatory cells can last for hours, even days) and accumulates well in the lungs and sputum. Though it has no effect directly against *P. aeruginosa*, it can fight Haemophilus influenzae as well as *Staphylococcus aureus*. And it has a history of effectiveness for treatment of ear infections and non-tuberculosis mycobacterium in children. This track record reduces concerns about resistance to *P. aeruginosa*. Additionally, a recent study involving the use of Zithromax for patients with CF indicated some improvement in lung function and an increase in weight. Also noted was some reduction in hospitalizations, IV antibiotics, oral quinolone and non-quinolone antibiotics. Researchers are still unsure of its mechanism, but it is believed to have anti-inflammatory and mucus thinning properties. The drug is considered safe and tolerable.

Studies regarding the use of inhaled Tobramycin (TOBI) have shown its ability to knock down *P. aeruginosa*, only to have it eventually grow back. The important question now is to determine how long *P. aeruginosa* can be eradicated or controlled using TOBI, if TOBI will improve lung function, and if a resistance to this antibiotic and others will emerge.

The bottom line is that we will never know the answers to these questions without performing clinical studies. These studies can't be done on non-CF patients or animals. Participation by those who have CF will move this investigation forward. When approached to be a participant in a clinical study it's best to be open about it. Get educated about the study and understand the risks in order to make an informed decision. And if this works for you, know that you are an important player in the quest for a cure of CF. ■

## Fourth of July Barbeque

By Katelyn Tornroth



Altano Family

To honor Cystic Fibrosis Research, Inc., every year friends and family of Gianna Altano gather together for some barbeque, fun, and fundraising! This event takes place in the Aptos Creek Park of Aptos, California on the 4<sup>th</sup> of July. The enthusiastic volunteers sell all kinds of goodies for the crowds of people who gather for the "world's shortest" parade.

The fundraising event began several years ago, when Gianna's younger sister Marissa begged her dad, Danny Altano, for a hot dog. To his surprise, "American" food was not available to be purchased at the parade. This led Danny to a brilliant idea! He made his way to the Seaclyff Inn in Aptos and asked his friends if they would be willing to help with a fundraiser booth at the following year's parade. The friends agreed, knowing they would be responsible for 80% of the work. Five years later, this very special fundraiser averages \$5,000.00 in sales and donations from local businesses all over Santa Cruz County.

"We do this every year," says Danny, "not only for my daughter, Gianna, but also in memory of Adam Oneto, Gianna's friend. He passed away due to the severe effects of Cystic Fibrosis. It was a great loss, and in a small way we want to keep the memory of his love and life alive in all of us." ■



Annual 4th of July Barbeque

## Breathing Room Exhibit at 2003 CFRI Conference

By Michelle Compton

Breathing Room is an independent non-profit organization that took shape under the direction of an adult with cystic fibrosis, Michelle Compton. Six years ago, Michelle was in endstage with CF when she conceived a project to express the journey of life with cystic fibrosis through photographs. Supported by friends, family, and the donated services of professional photographers, a gallery grew called "Through the Looking Glass: Images of Adults with Cystic Fibrosis."



Diana and Michelle Compton

Since 1997, this collection has grown each year in number and scope. Individual photographs capture moments in time, feelings, and expressions of what it is like to live with cystic fibrosis. The adults who participate in this project lend their words to each photo. There are now 30 images which offer a wide spectrum of what life with CF looks like – the highs, the lows, the anger, grief, gratitude and love.

In 2003, Breathing Room launched a new project, "Through the Looking Glass: Caregiver Stories." This shares the same format as the original Looking Glass project - photographs and text - but opens the opportunity to those who love someone with CF to share their experience. In one short year, Caregiver Stories (under the direction of Robin Modlin) has created 12 images reflecting the cystic fibrosis experience of parents, doctors, friends, respiratory therapists and grandparents.

This year Breathing Room returned to exhibit these projects at the 2003 CFRI Educational Conference. We were honored to be invited to come again. The conference committee took care and thought to intertwine the photos from Breathing Room throughout the conference area. Many of the Caregiver Stories were featured in the banquet room, and offered people a chance to get up-close to the photographs, take time to read the writings during the less hectic times of the information-rich conference. The original "Through the Looking Glass: Images of Adults with Cystic Fibrosis" series was displayed centrally in the lobby, and served as a reminder of the bond we have as a community – to share, to learn, to support and to cope with this disease and the people it affects.

Breathing Room is currently collaborating with CFRI on events for their next conference in August, 2004. We hope to see you there. For more information on Breathing Room, its projects, or how you can participate, please visit [www.thebreathingroom.org](http://www.thebreathingroom.org). ■

### Living Well (Continued from page 14)

topics: providing healthy eating and exercise, teaching social skills, developing communication skills, managing emotional consequences, managing the marriage relationship and sibling issues, dealing with depression, handling school issues, managing adherence to the treatment plan, working with the healthcare team, making informed treatment decisions and planning for the future.

After taking the class, parents discussed what was most helpful for them:

- It was great sharing our thoughts and feelings so we know we are not alone.
- I liked being reminded of good health practices.
- It was beneficial learning techniques for dealing with problems.
- The class was very valuable and I made some new friends.
- The teachers offered great ideas for successfully managing problems and offered their invaluable personal experience with CF.

If you would like additional information about these classes and future classes, please contact Isabell Stenzel Byrnes at [isabear27@hotmail.com](mailto:isabear27@hotmail.com) or Ann Robinson at [arobinson@cfeducation.net](mailto:arobinson@cfeducation.net). ■

# CFRI Featured at American Lung Association's Bike For Breath

By Ana Stenzel

On July 12, 2003, the American Lung Association of San Francisco and San Mateo County held its 12th Annual Bike-for-Breath benefit bike ride in Foster City, California. CFRI Board member and volunteer Ana Stenzel organized a team comprised



*Participants in the Bike for Breath Ride*

of three lung transplant recipients, 2 people with CF who are awaiting lung transplants, and 31 other family members, friends and co-workers. The team called "Second Wind," had the aim of raising awareness about lung transplantation and cystic fibrosis in the greater lung disease community. Over 900 cyclists participated in the ride. Cyclists had the choice between a 16,30,80 and 100-kilometer ride. Ana Stenzel's brother, Ryuta, who does not have CF, gave it his all in a valiant effort finishing the 100-kilometer ride in less than 4 hours. Isa Stenzel-Byrnes and Lara Borowski, both awaiting lung transplants due to CF, successfully accomplished the 16 km (10 mile) ride, with oxygen tanks on their backs. Lung transplant recipients Judy Black and Marilyn Hom, who were transplanted for lung diseases other than CF, succeeded in riding the 16-kilometer ride as well. CFRI community members Ed Kinney and Andrew Byrnes were among the 36-team members.

In exchange for successful fundraising efforts, the American Lung Association provided CFRI and the California Transplant Donor Network a booth at the ride's finish line. CFRI and CTDN drew interest from spectators who were curious about cystic fibrosis and organ donation. It was the first time that the American Lung Association welcomed a CF community group to its event. It was a unique opportunity to educate the greater lung disease community about CF and to raise awareness that lung transplantation offers hope to sufferers of all lung diseases.

Team Second Wind raised over \$2,300 for the American Lung Association. The team received an award for the "most spirit" and for raising the most money among teams comprised of family and friends. Collectively, the Bike-for-Breath raised over \$23,000 for the American Lung Association, making it the organization's biggest fundraiser of the year. The American Lung Association funds various lung disease prevention and education programs, such as asthma management in schools, tobacco cessation programs, and public policy work for air quality, tobacco and asthma programs.

I would like to sincerely thank the many members of the CFRI family for graciously sponsoring Team Second Wind and making our fundraising efforts so impressive. We truly appreciate your support. We look forward to making this an annual event and welcome any future participants! ■



## Introduction to Cystic Fibrosis

### A Video for the Newly Diagnosed Family.

Denver Children's Hospital Cystic Fibrosis Center, in conjunction with Digestive Care, Inc., makers of PANCREARB®, the only bicarbonate buffered, delayed-release capsules, have produced the premier video for the newly diagnosed family.

**Introduction to Cystic Fibrosis** is the newest and most comprehensive video available for the newly diagnosed family as well as a refresher for current parents and caregivers. It describes the roles of the various healthcare professionals in the CF Care Team. The nurse, respiratory therapist, physician, social worker and dietitian each play an important role in the care of the cystic fibrosis patient and the well being of the family. It also covers some treatments, which may be recommended for the patient such as the use of enzymes, chest physical therapy and antibiotics.

The family and caregiver of a newly diagnosed patient are often presented with an overwhelming amount of information at their initial meeting with the CF Care Team. This video allows the family to review the roles of the team members and their responsibilities in their own home at their own time.

This is the most comprehensive guide for newly diagnosed families and caregivers available. For your copy, please contact your CF Care Center or contact Digestive Care, Inc. at [www.digestivecare.com](http://www.digestivecare.com), 610-882-5950. ■



# In honor of

(From April 26, 2003 to December 31, 2003)

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

Do you have a relative or friend whom you would like to celebrate/salute? Are you searching for the perfect birthday present, wedding or anniversary gift, graduation gift, etc.? Give a gift with lasting impact – make a donation to Cystic Fibrosis Research, Inc. 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, Bayside Business Park, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043

John	Roger Burschinger	Hayden Ellett	Bonnie Grossman	Edward Kinney	Anna Modlin	Thomas Reed	Otis Stracener
Lucy	Harriet Butts	Jennifer Ellis	Anita Haberl	Michael Kinsley	Alex Molle	Mrs Paul Reschick	Blair Strohn
Jonathan	Isa Byrnes	Brad Epstein	Sonya Haggett	Lori Kipp	Alex Moore	Paul Reschick	Swanson Family
Maureen	Jerry Byrnes	Annie Jeffre Estes	Alex Hampton	Bridget Klein	Angela Moore	Melissa Reta	Delinda Syme
Kathy Abeles	Kandra Cady	Alisa Evans	Liz Hampton	Julie A. Kobernus	Angela Morey	Cortney Reuscher	Rodger Tauman
Rick Abeles	Dara Cameron	Randy Evans	Dave Hanna	Bill Kolchin	Nick Morey	Michael Reuscher	Heidi Tegner
Chelsa About	John Cameron	Tom Evans	Angelina Hannas	Eleanor Kolchin	Olivia Morris	Diddy Rivers	Pat Thibault
Connor Achison	Sean Campise	Bart Favero	Willie Harbison	The Kolchin Family	Kathy Morse	Tom Rivers	Frank Thibault
Adam Aliotti	Warren Carlund	Joan Favero	Juliano Harding	Jason Konkel	Ann Marie Murphy	Rebecca Roanhaus	Thibault Family
Jimmy D. Allison	Laura Carlson	Mrs. W Aubrey Federa	Monica Harding	Santosh Krishnan	Charles Murphy	Ben Robertson	Adam Thompson
Gianna Altano	Richard Chartrand	Dr. W Aubrey Federa, Jr.	Carleton Hardy	Steven Kusalo	Joseph Murphy	Ann Robinson	Lauri Thompson
Tyler Amsterdam	Virginia Clapham	Patti L. Ferguson	David Hardy	David Lagasse	Tom Murphy	Carl Robinson	Lorrie Thon
Sadie Anderson	Ryan Coelho	Alanah Fink	McKenna Hardy	Nancy Lane	Linda Myers	Clare Robinson	Shell Trask
Stanley Anderson	April Cogdell	Lorin Fink	TJ Hardy	Timothy Laufenberg	Janice Nahara	Rob Robinson	Todd Trisch
Alex Ard	Eleanor Collins	Jarrold Fischer	Brendan Harrigan	Lawrence Lavagnino	Christine Nash	Cortney Roeder	Robert Turk-Bly
Polly Armstrong	Lauren Colonna	Taylor Fisher	Barbara Harwood	Dylan Leaphart	Kim Nelson	Rebecca Roger	Jennifer Uskoski
Elizabeth Arvidson	Mrs Richard Colten	Kim Fiske	George Hawley	Barbara Lenssen, Ph. D.	Chuck Nelson Family	Kathleen M. Rolefson	Gail Van Vleck
Jessica Arvidson	Richard Colten	Victoria Flamence	Georgette Hawley	Michael Livingston	Jessica Nett	Donna Romano	Jan VanDyke
Patrick Aspinall	Cameron Cornell	Pat Flynn	Tyler Heavner	Rose Logue	Sharon Niederhaus	Sarah Rosenthal	Tom VanDyke
Rebecca J. Atkins	Kellie Couch	Jason Foster	Christian Heavner	Jennifer Longoria	Eugene Northcott	Milt Rosenthal	Bets Viering
Jaimee Baker	Lavergne Cowden	Ryan Foster	Abby Heilman	Alyson Lowery	Jack O'Brien	Jason Ross	Betty Vitousek
Haleigh Baker	Laura Cramp	Scott Foulger	Max Heilman	Tom Lufft	Pat O'Brien	Andrea Rothbart	Matt Vitousek
Kyle Baker	Marva Croaff	Joseph Fraker	Dianne Hoff	Virginia Lyons	Ben Oneto	Siobhan Ryan	Robert Vogel
Ron Baldwin	Laura Cryan	Jacob Fraker	Steve Hoff	Susan L. MacKenzie	Naomi Oneto	Andrew Sabatino	Brendan Wakefield
Ann Baldwin	Barbara Curry	Cody Franks	Susan L. Hoffman	Ron Mardigian, Jr.	Alymaris O'Reilly	Katelyn Salmont	Devin Wakefield
Lucy Barnes	Jim Curry	Georgette Franks	Jeremiah Holdaway	Ashley Marea	Killian O'Reilly	Ben Sanford	Aaron Waldrum
Jamie Barry	Caroline Daly	Jessie Franks	Joshua Holdaway	Larissa Marocco	Madden O'Reilly	Amy Sanguinetti	Christopher Walton
Joseph Batchelder	Olivia Daves	Lea Franks	Taylor Holm	Danny D. Martinez	Annette Palmer	Ericka Schlotterbeck	Viola Wastell
Marilyn Bates	Ashley Davila	Rebecca Franks	Hayley Horn	Helen Maschino	Dustyn Parson	Mary Schott	Kassi Watkins
Makinnon Baugh	Andree deJong	Judge Fratianne	Ben Horton	Finney Maschino	Andrew Peak	Joe Senn	Brett Watts
Marin Baugh	Cynthia deJong	Peggy Fratianne	Millie House	Glen Matson	Bill Pelzl	Marilyn Senn	Christopher Wernli
Irwin Beltrame	Edward deJong	Emily Fredrick	Anne Houston	Helen Matson	Erica Pescht	Janice Shaul	Ricky Whicker
Kay Beltrame	Charlie Delgado	Jessica Fredrick	Erin Hoyt	Nahara Mau	Lamar Pescht	Rob Shore	Eliza Ming Williams
Brenda Bennett	Marty Detrick	Abbie Freiley	Clark Huddleston	Corey McAllister	Tanya Pescht	Rachel Silver	Joseph Williams
Brett Bennett	Gordon DeVore	Linda Gagnon	Lola Hunt	Claire McCabe	Barbara Peterson	Joseph Sinnaeve	Marlene Wine
Sharon Berger	Lauran Dobos	Natasha Gaziano	Robert Hunziker	Spankey McCoy	Stephen Peterson	Sarah Skeffington	Jeff Wine
Amanda Bergman	Joe Donahue	Mark E. Gerow	Will Huston	Olga McCoy	Dale Peterson	Joyce Slama	Nina Wine
Alyson Best	Robin Donaldson	Shirley Gilles	Richard Jackson	Sam McDonough	Kent Peterson	Travis Smalley	Chuck Witt
Brooke Ann Bettis	Josep L.V. Donaway	Janise Giuliano	Tessa Jacobson	Russell McKlem	Erin Phillips	Brian Smith	Joy Witt
Earl Beydler	Dr Jill Doran	Larissa Giuliano	Alex Jenkins	Rachel McMullen	Jereme Pierce	Matthew Spadia	Denise World
Oliver Biggar	Luke Dorman	Ashleigh Godfrey	Carroll Jenkins	Rebecca McMullen	Kaeti Pierce	Megan Stacy	Josiah Woodhouse
Aidan Biggar	Danny Driscoll	Jennifer Gold	Steve Jenkins	Carly McReynolds	Mark Pizzelli	Robert Staggs	Rachel Woodhouse
Joseph Botts	Ann DuFrane	Craig Goldberg	Melody Johnson	Stacey Hawes Melle	Melissa Predny	Mrs. Robert Staggs	Emily Woods
Ryan Botz	Duke DuFrane	Bryan Goldberg	Michelle Jones	Nancy Melvin	Bune Primack	Jane Steele	Brian Woodworth
Rebecca Boyer	Matt Dunn	Elyse Goldberg	Peter Judge	Jacquelyn Merrill	Dr. Marvin Primack	Henry Steele	Thelma Worthen
Pat Brendt	Tess Dunn	Stephanie Goldberg	Ed Kenny	Betty Meyers	Robyn Primack	Lisa Steiding	
Nicole Burgess	Raymon Duntun	Raymon Goldstein	Jeremy Kharrazi	Jeremy Kharrazi	Justin Rains	Doreen Steneberg	
Brian Burks	Nancy Durette	Diana Goodman	Tracy Kiles	Fiona Mischel	Cynthia Rappaport	Ana Stenzel	
Kevin Burleigh	Maxine Eggerth	Phillip Grasser	Frannie Kiles	Lucy Mitchell	Larry Rappaport	Robin Stevenson	
Patty Burschinger	Danny H. Ellett	Barbara S. Greenberg	Kay Kinney	Kim Mitchell	Briauna Red	Chuck Stockley, Jr.	

# Memorials

(From April 26, 2003 to December 31, 2003)

## **A memorial is a donation made in honor of a deceased person.**

The memorial gifts come to us not only for victims of CF but for their families and relatives as well. We extend our deepest sympathy to their families and friends. These gifts have given new hope to children and adults with CF. (Note: Occasionally someone who died had the same name as a living person.) Send name of the deceased, and the name, address, city/state and zip of the relative/spouse, etc., whom you would like notified that the donation was made. Send to: CFRI, Bayside Business Park, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043

Tom About	Jodi Armknecht	Cheri Brower	Peter Byram	Kyle Butler	Cassandra Cochran	Gladys C. Dana	Beth Daistein
Fern Adelman	Meghan Andrade	Greg Brazil	Mary Botti	Bill Cady	Rachael Crocker	Joshua Dadami	Lester Day
Fred Adelman	Arlene Arnold	Michael Bowman	Frank J. Beck	Thelma Cady	Kelly Colgan	Neva DeVore	Brenda DiGiovanni
Kim Adelman	Peter Astiz	Anne Beltrame	Danny Baxter	Hannah Carcanague	Dorothy Cohen	Catherine Driscoll	Tim Driscoll
Sonya L. Akister	Audrey F. Baskett	Rodney K. Borden	Barney Bruno	Sonya Chartrand	Bob Churchill	Bonita Davidson	Jennifer Eisner
David Armknecht	Amy Bienenstock	Kristi Burnham	David Butler	Ann M. Cripps	Ernest Camino	Marty Detrich	John Eggerth

(Continued on page 19)

# Memorials (continued from page 18)

Karen Elems	John Ghiorso	KOKO	Matthew Mitchell	Floyd Maschino	Pamela K. Rockhold	Tammy Smerber	John Trask
Danny Emler	Jannie Hutchings	Blake Kelley	Fred Maisch	John Murphy	Randy Rupract	Craig Smith	Marge Trask
George Figone	Stephanie Halling	Jane E. Kulik	David McAfee	Kim Myers	Catherine Rawlings	Donald Smith	Dr. James Theodore
Pam Faulk	Cindy Haley	Jennai Kodis	Dennis Manning	Elizabeth Nash	Barbara Roth	Jamie Smolin	Roxanna Thomas
Lorrie Fulton	Sean B. Hyland	Justin Kennedy	Mollie Miller	Rodney K. Neault	William Ruffner	Mary L. Settle	Thibault Children
Georgette Francis	William Haney	Dawn Longero	Howard Moore	Scott Nelson	Tom Rolefson	Melissa Stone	Linda H. Trojak
Tatum Ferguson	Eleanor Hill	Lawrence Leuck	Jennifer Montgomery	Coy Newsom	Allison Roberts	Dave Stuckert	Aurore Vaeth
Ben Faber	Robert Holm	Mamie Lilly	Dave Martin	Ellen Ott	Frankie Rosenfeld	Laurie Stuckert	Jerry Vaeth
Tony Favero	Ralph Harmon	Emma L. Levin	Robert McGillis	Michelle Olsen	Dhea Schalles	Mel Stuckert	Erik Van Ness
Margaret Favero	Fran Hartman	Eileen Ludwig	Jerry Mann	Adam Oneto	Michelle Sanderson	Charles Stockley, Sr.	Ray Van Garsse
Fred Garibaldi	John Holmes	Peggy Lana	Fred Marion	Roger Passero	John Saidy	Melissa Stone	Vertie Vandervort
Elizabeth S. Gordy	Michael Hospodar	Jerry Lay	Marjorie McDowell	Jon Prater	Karen Shores	Walter Sieg	Joy Villasenor
Isaac Goldman	Leslie Hotson	Lawrence D. Lewis	Lucy Marsh	Tim Prater	Sandra Schiral	Agnes Schnathorst	Tom Walton
Sherwin I. Greenberg	Stephanie Huff	Betty Lamb	Glenn Michelucci	Shawn Peterson	Sandi Schuckel	Eileen Stallings	Dorothy Whalen
Tina Groleau	Kathy Judge	Lynette Moulton	Michael E. Moore	Erica M. Peralta	Diana Segal	Mildred Stockley	Keagan Wahler
Richard Guaydacon	Ashley Johnston	Tom Murphy	Steve Minor	Jeremiah Pfau	Virginia Shumate	Beatrice Stagnaro	Roy Whaley
Alan S. Golden	Gerold Juelch	Jessica Mobley	Ruth H. Martensen	Terry Phelan	John T. Sexton	Jennifer Smith	Hayley Wester
Jerry Gravkin	Melody Johnson	Ross Moran	Jean Merwin	Gladyce Pearl	Raymond Steele	Linda Scherschel	Howard Walton
Agnes Goehring	Ulilla Johansen	Betten Marks	Paul Matthews	John Runge	Ernest Sattler	Dresden Tingley	Sanford Ziegler

## Become a Member of CFRI!

You can become a member of CFRI for just \$25.00 per year (or \$40.00 for a family membership). By participating in our community – whether you live nearby or across the ocean – you promote the importance of cystic fibrosis research and education. Join us at our semi-annual meetings. Your ideas for the growth and development of the organization help to guide our funding priorities. To be accessible to our membership and to keep us in compliance with California non-profit law, we have revised our voting policies.

Our membership year begins in mid-September in anticipation of our October meeting. **Having paid annual dues, any member can become a Voting Member by writing to CFRI with that request or checking the appropriate box on the form below and sending it in.** Voting information will be sent to all Voting Members 30 days prior to the May and October General Membership Meetings. Ballots may be returned to the office by mail and must be received by the day of the meeting. Alternatively, ballots received by e-mail or fax must be received by noon Pacific Standard Time on the day of the meeting. Those who have CF and are at least 18 years of age, or those who were lifetime members as of May 29, 2003 must also make an annual request in writing to participate as Voting Members. The Voting Membership is set, for purposes of establishing the quorum number for the year, on the date the voting information is sent out to the voting members – around the third week in April and September. Membership involvement in CFRI energizes and strengthens our organization. We look forward to hearing from you! Please contact us if you have any questions: email us at [cfri@cfri.org](mailto:cfri@cfri.org) or telephone 650-404-9775.

To become a member of CFRI, complete the Action Coupon below and mail it to our office: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043. Should you further elect to become a **Voting Member**, simply check the appropriate box below and note the name(s) of voting member(s). [A family membership covers two Voting Members.] Registering as a Voting Member entitles you to vote on major decisions such as allocations of CFRI research funds, bylaw revisions and changes to the Board of Directors. **Note:** Our "Lifetime Membership" is no longer available. If you were a lifetime member prior to May 29, 2003, you are guaranteed that membership henceforth. We ask you to complete this coupon with updated information and indicate if you would like to participate as a Voting Member. If you have cystic fibrosis and are at least 18 years of age, your dues are waived. Please complete the information below so we can update our database as needed, and indicate whether you would like to participate as a Voting Member.

## CFRI Membership Coupon

- Here is my annual membership (check one): \_\_\_ Individual (\$25.00) \_\_\_ Family (\$40:00)
- I have cystic fibrosis and am at least 18 years of age. I would like to be a member. *(Annual dues are waived.)*
- I was a Lifetime Member prior to May 29, 2003. *(Annual dues are waived.)*
- I am an existing member, have paid dues, and would like to register as a Voting Member: \_\_\_\_\_ *(Signature required)*
- I prefer to be a donor only.     Please remove my name from your mailing list.
- I would like to participate in the Mothers' Day Tea in 2004 as a Tea Sender.

Name \_\_\_\_\_ Affiliation with CF \_\_\_\_\_

Street \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Date of Birth (Adults with CF) \_\_\_\_\_ Telephone \_\_\_\_\_ E-mail \_\_\_\_\_

*CFRI's mailing list is confidential: we do not give out any names or addresses under any circumstances.*

**All Membership dues are 100% Tax Deductible.**

# ABOUT CYSTIC FIBROSIS AND CFRI

CF is the most common life-threatening, hereditary disease in the U.S. More than ten million Americans are symptomless carriers of the CF gene. One in 3,200 American children is born with CF.

Symptoms may include:

- persistent cough, wheezing or pneumonia
- loose, foul-smelling stools
- heat prostration
- abdominal pain
- excessive appetite, but poor weight gain
- salty-tasting skin
- clubbed fingertips

CF patients suffer from chronic lung disease and digestive disorders that may require frequent hospitalizations. At present, only half of those with CF survive to age 33.

## ABOUT OUR FUNDRAISING

Cystic Fibrosis Research, Inc. raises funds through a number of channels:

- Personal mail solicitations
- Memorial and In Honor Of gifts
- Grants
- Special fundraising events
- Membership fees
- General donations

## CFRI's E-MAIL ADDRESS AND WEB SITE

CFRI's e-mail address is: [cfri@cfri.org](mailto:cfri@cfri.org). Use this address to obtain information about our organization, the latest word on cystic fibrosis, or to communicate with our office. Also check out our Web site: [www.cfri.org](http://www.cfri.org). See you on the Internet!

## ABOUT OUR SERVICES

CFRI offers the following services:

- Research funds awarded to scientists at major medical research centers
- Educational meetings for the CF community
- Annual CF Educational Conference
- Annual CF Retreat for ages 15 to adult
- Family support groups
- CF support groups for ages 15 to adult
- *CFRI* Newsletters
- E-mail and telephone referrals and support services
- Videotapes and CDs of meetings and conferences

## ABOUT OUR SUPPORTERS

CFRI is a nonprofit, volunteer organization not affiliated with any other group. Our support comes from the dedicated volunteers and staff including:

- Executive Director, Program Services Manager, Administrative Assistant, Database Administrator
- Research Advisory Committee of physicians, scientists, and members
- Board of Directors and Executive Committee
- Advisory Committees
- General membership
- Mothers' Day Tea senders
- Office volunteers

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**Special Thanks:** CFRI wishes to thank Chiron Corporation, makers of TOBI®, for their generous support of *CFRI News*.

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Cystic Fibrosis Research, Inc.  
2672 Bayshore Parkway, Suite 520  
Mountain View, CA 94043

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## *Spring 2004*

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