

CFRI

33 Years of Research, Education & Support

CFRI's Annual Education Conference In It To Win It!

Over 200 people from across the country attended the 20th Annual Cystic Fibrosis Research, Inc. Conference August 10-12 at the Sofitel San Francisco Bay. This year's program was: "In It to Win It: Successful Strategies for Living Well with CF".

Speakers included medical doctors, researchers, physicians and scientists from the U.S. and England who shared their knowledge and answered questions. A separate track for highly technical CF topics allowed researchers and scientists to update attendees on their respective research projects.



Conference attendees, sponsors, researchers, presenters and guests actively engage as CFRI kicks-off their 20th annual three-day CF Conference.

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The United States Adult Cystic Fibrosis Association (USACFA) collaborated extensively with CFRI this year. They shared their life experiences in a delightful presentation in rhyme on Friday evening in the style of Dr. Seuss. Thanks, USACFA!

Topics in the general three-day program included: *Clinical Treatments of CF, Developing Healthy Eating Strategies, Advocating for Best Care, Financial Planning and Effective Strategies for working with School Systems*, among others. There were several panels held to answer questions: one comprised of parents who had raised CF children to adulthood, a second of top medical and scientific researchers to address technical questions, a third to answer financial questions.

CysticFibrosis.com brought their camera crew to film interviews they conducted with presenters and participants. Check their CFtube to see someone you know!

CF patients, families and friends attended support groups and had a chance to relax in the Starlight Hospitality Suite.

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Fall Update

RESEARCH Your CFRI Dollars at Work

By Darlene Batchelder

The CFRI conference was a unique opportunity to hear the latest updates from the Elizabeth Nash Memorial Post Doctoral Fellowship researchers whose work we fund. While the presentations were fairly technical for a lay observer, I felt heartened by the inquiry and excited discussions among the researchers.

Dr. Terry Machen, Ph.D. from the University of California at Berkeley presented his work on the hyper-inflammatory response to infections that occurs in CF lung tissue. He summarized: "It is well known that the lungs of CF patients become highly inflamed with a massive influx of white blood cells (neutrophils) that attempt to fight bacterial infections. The exaggerated inflammatory response results ultimately in tissue destruction and reduced lung function. It has been

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Notes from Our Executive Director

At our 20th Annual Education Conference and our Annual Teen and Adult Day Retreat, CFRI shared exciting research reports, presentations, support groups/rap sessions and warm hospitality. In this issue you will find reviews of these events and a listing for our DVD's that make the presentations available to those who could not join us. Our new DVD burner from the Los Altos Sunset Rotary allows us to turn your orders around quickly!

This year's Conference celebrated the implementation of the California Newborn Screening Program for Cystic Fibrosis which was launched in July. Thanks to our distinguished guests for making this happen: Catherine Comacho, Deputy Director for the Center for Family Health, California Health Department; to her staff; to members of the Genetic Disease Screening Program; and to Liz Figueroa who introduced SB 1748 last year.

We were joined by the team at CysticFibrosis.com who captured a different perspective of the Conference by videoing interviews with speakers and audience members. Check this out! www.cysticfibrosis.com.

The Peter Judge Legacy Program returned this year with a summary of last year's interviews at Conference '06. That information served as a springboard for a collaborative effort between Stanford's Center for Education in Family and Community Medicine, the Institute of Transpersonal Psychology and CFRI: The CF Counsel-

ing Program. Through this unique program, counseling will be available to the regional CF community, patients, caregivers and medical staff.

Thanks to Digestive Care, we have new 2007 editions available of *CF in the Classroom* and our *Cystic Fibrosis Website Guide*. These CFRI publications have been requested around the world from Australia to Poland to Paraguay. We are pleased to send you copies for yourself, your school and other care-givers.

Our CFRI research programs, the Elizabeth Nash Memorial Fellowship and the New Horizons Campaign, continue to be an important investment in a healthier life for those with CF. The projects we support give us vital information about the disease and move us all that much closer to a cure.

Thank you all – donors, sponsors, volunteers, members – for your generous support. You make all of this possible. Please stay in touch!

Warm regards,

Carroll Jenkins

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Around the Corner

Calendar of Events

December, 2007

RETREAT HOLIDAY PARTY

February, 2008

MOTHERS' DAY SENDER'S KICK-OFF TEA

August 1-3, 2008

CFRI'S 21ST ANNUAL EDUCATION CONFERENCE

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

August 3 – 8, 2008

CFRI DAY RETREAT

Vallombrosa Center, Menlo Park, CA

Advocating for the Best Medical Care

How To Work With Your Health Team To Achieve The Best Results

In It To Win It!

Joan DeCelle-Germana, M.D., presented tips and suggestions for getting the most out of your time with CF physicians and health-care professionals. As a mother of three boys and a physician specializing in CF herself, her experience and expertise resulted in a presentation filled with tips, advice and suggestions.

She shares with parents five guiding principles:

1. Knowledge is power;
2. Ignorance is not bliss;
3. Educate yourself;
4. Use trustworthy resources;
5. Your CF team has relevant experience.

She knows parents can be under stress and have limited time, so advised, "Write down your questions and bring them with you." She advocated keeping a notebook where you can record conversations, test results, any sheets given to you by care givers – so all the information is in one place. "You'll learn to be a great multitasker because there is so much to do in a day and it all begins with organization. We know it's difficult to remember all our conversations so we rely on written instructions. Ask your care givers to make sure you can take written directions with you. Be honest with the staff. Your physician can't provide the proper diagnoses if you're telling your doctor you're doing all the treatments and you're not. We're all human," she said.

Tips to remember: Sometimes enzymes are outdated or have been sitting in a car glove box and are no good. Occasionally generic substitutes don't work as well. In terms of eating, have a plan. You can't win the battle when it comes to food so don't let it become a battleground. Follow basic recommendations in terms of regularly scheduled appointments at your



Joan DeCelle-Germana, M.D., Director of the CF Center at Schneider Children's Hospital

CF center. Have blood sugar tested and check for diabetes annually from the time the patient is a teen.

Ask questions. Your doctor's job is to educate you and there's never a dumb question. "No one expects you'll understand it the way we do, but we don't suspect you're not bright. If I'm stumped and don't know the answer, then we'll figure out where to go to find it." Dr. Germana also reminded us to "quit smoking." When you have someone in the house or car with CF, smoking is a real added threat to their health.

There is a reason for a full CF team. Some patients don't like to meet with the social worker or the nutritionist but it's all part of an overall care plan. In all CF centers, you'll be tested for lung function and they'll run a sputum culture. Your BMI (Body Mass Index) is recorded for all patients more than two years old. You should

know these basics and keep track yourself of improvements or drops in weight, lung function or other areas. Post written discharge instructions on the fridge with a magnet and follow them.

Finally, she reminded the audience, "You have to take care of yourself." She stressed

"You can't win the battle when it comes to food so don't let it become a battleground."

some basics, such as spirituality, getting daily exercise and reading. (She works Sudoku puzzles just before going to sleep to keep her mind active.) She advocated the book, *The Secret*, because "everything starts with a thought." She ended her presentation with a quote from Henry Ford: "Whether you think you can or think you can't, you're right."

Getting the best care from your CF center means doing some homework yourself, following suggestions, asking questions when you're in doubt, taking care of yourself too, and being prepared (and on time) for your medical appointments.

The Battle Over Food

Developing Healthy Eating Strategies for CF Children and Adolescents

Bryan Lask, Ph.D., flew in from London to present his views as a psychiatrist dealing with young CF patients and their eating habits. Dr. Lask has a long-standing interest in both CF and in eating disorders. He has held Visiting Professorships in Australia, Norway and Canada and has published over 150 papers and 10 books.

A number of factors make it difficult for those with CF to eat healthily. These include:

- A very high recommended daily calorie intake
- An unpalatable diet
- Disease process – feeling unwell
- Poor appetite
- Recurrent coughing
- Abdominal discomfort
- Age-related expression of autonomy
- Parent-child conflict
- Self-image and body-image concerns
- Clinician's unrealistic expectations
- Family anxiety

In addition there are a number of feeding and eating difficulties not specifically related to CF that may further complicate the situation, including:

- Feeding problems of infancy
- Food avoidance emotional disorder (FAED)
- Selective eating
- Functional dysphasia
- Anorexia nervosa
- Bulimia nervosa

Consequently, meal times are often fraught, over-long and conflict-laden, leading to intensification of eating difficulties and a vicious cycle. The satisfactory promotion of healthy eating strategies is dependent upon any number of considerations. What to do about this – we need to think about social, biological and psychological factors. The crucial components of good management

of eating difficulties are a comprehensive approach, quality team work (working toward the same goal), clear leadership, agreement on a plan, clear roles, responsibilities and documentation. Include everyone in the plan and then apply it consistently for at least three weeks before expecting changes based on results (it always takes time to get used to a new plan). While this may sound formal, it works.

Focus on choice and motivation with additional areas as outlined here:

- Clear communication
- Consistency between each other and over time
- Therapeutic alliance (if needed)
- Working WITH the CF person
- Respect for age appropriate autonomy
- Respect for individual differences
- Allowing for what's possible
- Avoid coercion
- Battle against the CF not the patient;
- Motivation is a prerequisite for change
- A poorly motivated person will resist change
- Eating better is dependent upon enhanced motivation and motivational therapy

Giving someone choice is key to having someone buy into their decisions. If we deprive people of choice, there is a good chance they won't make a difficult change on their own. And yet we worry, focus on choice and motivation. What to eat? – When to eat? – Where to eat? – How to eat? – With whom to eat? – Who sits where? – What to wear? – What music to play during dinner? The more choices the patient has the better. Toddlers and teenagers need choices and factoring in all the choices above gives the patient literally a million different options.



Bryan Lask, Ph.D. is Emeritus Professor of Child and Adolescent Psychiatry at St. George's University of London, Medical Adviser to the Huntercombe Hospital Group, UK, and Visiting Professor in Oslo, Norway.

In It To Win It!

Q&A with Dr. Lask

Are bribes useful, e.g. monetary reward? *"Yes, but with an enormous 'but.' They work if they are immediate (a star going on a chart), if they are fun and implementable. You can't say we'll get you a better Christmas present and expect a bribe to work."*

Are threats useful e.g. tube feeding? *"No, no and no."*

Nutritional food vs. junk food? *"There is already a lot of anxiety, stress and perhaps anger over food. One can't eat, it's almost impossible, if they're under stress. If they'll eat it – let them eat it. Children usually outgrow unusual food cravings quickly."*

Can tube feeding in infancy lead to oral food aversion? *"There is very little evidence to support that – in fact I've seen only one example in my career."*

How do we know if she has an eating disorder? *"If there is an extreme preoccupation with weight and shape (I'm too fat!). In girls between the ages of 10 and 30, 90% feel this way at some time!"*

When can children be trusted to take their own medications? *"This is a gradual process of letting them take on more and more as they grow older. Some children can begin as early as five or even four to take some responsibility for their health and enzymes. As they grow older, use teamwork and plans. You can't take too much on yourself as there is a big change when patients go from children to adults."*

Special Thanks To Our Sponsors!

CFRI's annual programs would not be possible without the generous donations of our sponsors. Their support allows us to offer an affordable rate for conference attendees. In addition, we awarded eleven scholarships to attendees in need of financial assistance.

These sponsors generously contribute to fulfilling our mission:

For Mothers' Day Tea

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For CF Teen and Adult Day Retreat

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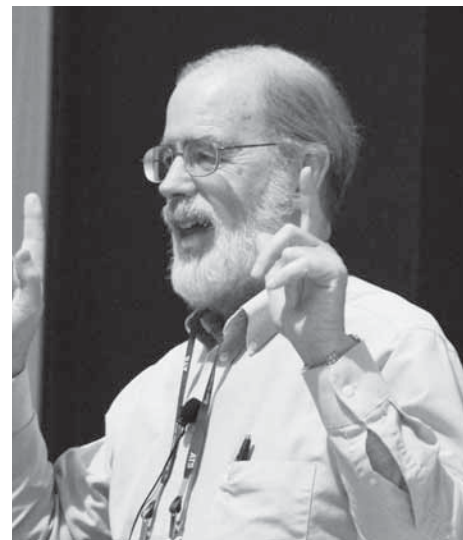
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Using More than One Antibiotic At A Time [★]

In It To Win It!

Working under the hypothesis that lungs with CF are destroyed by bacterial infections, not by intrinsic damage from the disease itself, it's critically important to keep them clear and functioning well, for as long as possible. "If you are well, do whatever you can to stay there," said Dr. Jeffrey Wine during his conference presentation.

Research done at his Stanford lab points to a preliminary tested, but unproven theory: *patients should ask their doctors to consider using more than one antibiotic at a time to eradicate bacteria and lung infections.* His theory of multiple drugs is similar to the current strategy for treating AIDS. So why hasn't this concept come into the CF world? "It's coming slowly," he said. "We have to convince doctors to use more antibiotics earlier and overturn old ideas about using them sparingly." Dr. Wine is carrying out a case study to test this theory and shared preliminary research during his presentation. Dr. Wine said, "When patients are critically sick, they are given antibiotics. But many other patients, especially in Europe, are given treatments all the time." The thinking is to keep the lungs as free and clear as possible, and keep them that way through the use of multiple antibiotics. The plain fact is as lungs lose their ability to function, they rarely if ever make a substantial come-



Jeffrey Wine, Ph.D., Director, Program in Human Biology, Stanford University, CA

back. You're left with eventual options of a transplant or death if they continue to deteriorate.

Dr. Wine's take home message: "Don't just wait for the next breakthrough. We have many tools to fight CF lung disease effectively today. Each of us must share responsibility for our own health. Speak up and be proactive, not reactive."

For a complete review of his one hour presentation, including more details on the tests from his lab, an overview of the theory and discussion of CF as two diseases, order a copy of his presentation on CD or DVD (info on page 14).



Scott Wakefield records one of the conference speakers as attendees listen and take notes.

CF Care Across The Country

In It To Win It!

CF Clinical Treatment:

What's New, What's Next?

“We believe that during the next five years the life expectancy of CF patients can be extended by 5-10 years through the consistent implementation of existing evidence-based clinical care.” This was the message brought to our conference by James R. Yankaskas who is currently Chair of the National Cystic Fibrosis Foundation’s Center Committee.

“As we’ve learned more about CF and how best to treat the disease, we’ve been able to establish standards for the 117 CF treatment centers, treating more than 24,000 CF patients around the country. We believe as we learn more, share what works with other centers, we’ll be able to continually extend the lives of CF patients just by doing ‘what works’ more consistently.”

Dr. Yankaskas included a short history to show “we’re making pretty good progress.” In 1955, the National CF Research Foundation was formed (name changed in 1961 to National CFF). The missions are to foster Care, Teaching and Research. CF Centers and a Center Committee were established. In the 1980’s the



James R. Yankaskas, M.D. Professor of Medicine, Pulmonary & Critical Care Medical Division, University of North Carolina at Chapel Hill, NC

main focus was basic research and 100% of the 1982 capital went to that end. In 1989 the CF gene was discovered. While we first thought there were only seven or eight CFTR mutations, we’ve since discovered over 1,500 mutations. This produces more challenges and more opportunities.

Clinical research increased greatly in the 1990’s, and has contributed to better care. This century we’re looking at more accountability for all the centers to insure that people get equitable care no matter what part of the country they live in. A written CF registry was begun in 1966. It is now internet-based and over 80% of

CF patients in the U.S. participate. This information is used to analyze care processes and outcomes, and to improve both across the entire CF Center network.

Looking to the future, Dr. Yankaskas described the CF Foundation’s seven worthy goals:

- Patients and families are full partners
- Normal nutrition and growth
- All receive appropriate therapies
- Control infection transmission
- Detect & manage CF related diabetes
- Support Lung Transplants & End-of- Life Care
- Equitable care for all

While these are long-term goals, the fact that measurement tools are implemented in CF centers nationwide means that today 87% of the centers are meeting these goals, with additional improvements being made continually.

Dr. Yankaskas works at UNC Chapel Hill. He says one of their continuing improvement mantras is, “Measure and learn, go toward the best.” Certainly a worthy goal to improve CF care.

Killing Bugs with Sodium Nitrite

A new way to kill *Pseudomonas aeruginosa* in lungs is proving very effective, based on initial test results. An article detailed in the prestigious *Journal of Clinical Investigation* earlier this year led to additional stories in the *BBC*, *NPR*, *The New Scientist* and *Reuters* on this study.

“A simple food preservative can kill this nasty bacterium *P. aeruginosa*,” said Dr. Dan Hassett during his presentation. “It’s simply their Achilles heel,” he said. “We killed them all – no residual bugs during initial tests.”

As lungs afflicted with CF become clogged with mucus and breathing becomes difficult, the bacteria are not adversely

affected because they don’t need air to grow. Thus an inhaled drug can be most effective. The inhaled Sodium Nitrite solution kills mucoid *P. aeruginosa* by overproduction of nitric oxide gas inside the lungs. Dr. Hassett’s current NIH grant will run through next August so additional funding for testing is needed, particularly to investigate what other “bugs” might be susceptible to this treatment and to test dosage requirements.

These promising early results led to an early stage respiratory drug development company being started last December by **ProQuest Investments**. For additional info contact: Daniel.Hassett@UC.Edu



Daniel J. Hassett, Ph.D., Professor, Dept. of Molecular Genetics, Biochemistry and Microbiology, University of Cincinnati College of Medicine



It's Great to Be Back

By Kathy Hardy

In It To Win It!

(Note: Kathy Hardy shares with our readers her own conference experiences and what they meant to her family. Kathy and her husband Tom have eight children, three with CF.)

I was glad to be back at the CFRI Conference this summer. Ever since the diagnosis of our oldest son David, 18 years ago, I've been a regular attendee of CFRI's annual education and support weekend. But two years ago with eight busy children I couldn't get away. And last year my husband Tom won the coin toss so he got to attend. So Tom had a weekend away and got his fill of visits with old friends and cutting edge CF research. This year it was my turn. It sure felt great to leave the hot Modesto Valley and get back to the cool Bay Area. And it was a joy to be back in the company of parents I have connected with almost every year for over a decade. Many of us met when our CF children were still babies. Our kids are getting older and we're entering "middle age." I had to laugh when I noticed the gray hairs and the way we all discreetly slipped on reading glasses when taking notes. The most significant difference for me was that my son David came too. He spent time at the CFRI Teen and Adult Day Retreat, so he rode over with one of his new friends and met me at the luxurious Hotel Sofitel.

I was also very proud to watch McKenna and her friend Macy play music for the early arrivers at the Friday evening reception. McKenna is our 14 year old

daughter with CF. She has become a talented flute soloist, rings hand bells in a youth ensemble, marches in her high school band and runs track. All of these activities have contributed to her continued good health. Besides the delicious food and the beautiful accommodations, the content of the conference was outstanding. Even David, who is definitely a product of the video game era, found many pieces of information interesting and intriguing.

The stimulating presentation by "Dr. Dan" (Hassett) on Friday truly got the weekend off to a great start. It was a definite high point of the conference. He introduced the idea of Sodium Nitrite, a common household food preservative, as an inhaled product to battle mucoid *pseudomonas*. David wanted to talk to Dr. Dan and see about getting into phase one trials as soon as they came about. It was thrilling to see David's enthusiasm. David and I took advantage of a short talk with Dr. Jeff Wine in the parking garage as we were leaving for the evening. He impressed upon us his excitement about Dr. Dan Hassett's research and is anxiously awaiting the results of the research trials.

Dr. Wine was one of many wonderful presenters on Sunday. I have had the privilege of hearing his research updates in the past and I found his presentation at this year's conference the most "user-friendly" ever. David paid close attention and took notes. I was ecstatic when David dragged me out of the lecture hall, sat me down in the hotel's lobby, and wrote

a four page outline of the treatments he planned on implementing. He also wanted to discuss with his new CF team the possibility of discontinuing some treatments. It was a thrilling experience to see David on fire about his health since he has appeared rather apathetic about his care over the years.

As usual, the support group was one of the most valuable times. Since David recently turned 18 and is a legal adult, I attended the support group for parents of adult children with CF for the first time. David attended the support group for adults with cystic fibrosis. I moved through the other groups over the years but I no longer have newly diagnosed or school age children with CF. We have two

high school children with CF besides David. The only negative comment I have about the support group is our time together was too short. It was wonderful to empathize with people who have similar experiences. We share victories and tips about what has worked with our families and what hasn't. Some have children who don't have CF and we shared how we manage the differences in raising children with different physical and emotional needs. Some of us cried along with those who were experiencing difficulties.

I was grateful to the many wonderful vendors who traveled from far and wide to represent their companies. They educate us about the countless new products and services now available. Many of the vendors also donate products for the raffle at Saturday's dinner. It is easy to forget that the staff and volunteers at CFRI work the whole year in preparation of such a successful and

(Continued on page 10)



Kathy Hardy



McKenna Hardy and Macy Ehman

An Overview of CFRI Research Projects

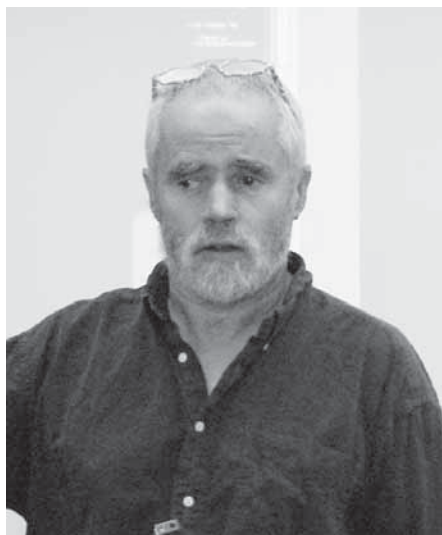
In It To Win It!

Your Research Dollars At Work – What Mysteries Are CF Researchers Unraveling In The 21st Century?

Since 2000, CFRI's Elizabeth Nash Memorial Fellowship has awarded thirteen fellowships to eleven separate laboratories. The published papers of these research efforts have appeared in twenty-four scientific journals and publications. The areas being pursued through projects funded by CFRI were highlighted at our conference by Jonathan Widdicombe, Ph.D., who serves as the Administrator of the Elizabeth Nash Memorial Fellowship.

A special aspect of this Fellowship is the ongoing collaboration that comes from semi-annual research roundtables to discuss progress, obstacles, ideas, etc. This interaction improves the quality of everyone's research and speeds the process of resolving common problems.

At the CFRI Conference, researchers discussed their progress in a separate, highly-technical track. If you want to understand more you may order a CD (or DVD to see slides) of Dr. Widdicombe's summary of their research. Dr. Widdicombe began with an elegant description of the CF



Jonathan Widdicombe, Ph.D. From 1989 to 2004, Dr. Widdicombe was Director of the NIH Specialized Center of Research in CF. He is currently a Professor of Physiology and Membrane Biology at UC-Davis.

disease process, followed by the specific challenges it presents to researchers. He quickly recapped previous research and then presented an overview of the latest round of CFRI funded research and why it's important. He spoke of our collaborative nature with regard to Fellowship meetings. "They have to play well together," he said. Finally, he noted the importance of finding researchers with expertise who are also highly networked with scientists doing related work, thus speeding the research process.

Scientists and researchers look to isolate questions they can test using the scientific method. CF has particular characteristics that lend themselves to investigation. Dr. Widdicombe listed a few of the themes and questions investigated during previous CFRI research projects:

- Does CFTR have effects inside the cell?
- What assays are recommended to investigate *Pseudomonas* binding?
- How is pH of airway surface liquid maintained?
- What is the best way to investigate the regulation of Na transport across the airway epithelium?
- What is the role of mucus glands in CF airway pathology?

Marybeth Howard, Ph.D., spoke about specific studies under the New Horizon's program. Dr. Howard serves as the Chairperson of CFRI's Research Advisory Committee (RAC) and her current research involves studying the regulation of CFTR maturation and trafficking

as well as the regulation of the STAT1 signaling pathway in acute lung injuries. This past year our New Horizon research funded three new researchers from the University of California, Davis; the University of Alabama, Birmingham; and the Medical University of South Carolina. For additional information on the New Horizon Research Campaign please refer to *CFRI News*, Spring, 2007 edition.



Marybeth Howard, Ph.D. is currently an Associate Research Cell Biologist in the Department of Anesthesia and Perioperative Care at the University of California in San Francisco.

At CFRI:

Our Research Advisory Committee (RAC) reviews research reports and provides insight and guidance for subject researchers. In addition, RAC regularly evaluates and makes recommendations to fund new research projects to CFRI's Board of Directors.



Your Research Dollars at Work!

(Continued from Page 1)



RESEARCH

Your CFRI Dollars at Work




argued that this hyper-inflammatory response of CF epithelial cells results in part from altered airway epithelial cell signaling caused by the absence of the functional CFTR chloride channel. Taking special care to assure the same genetic backgrounds of the cells, we found that CF and CFTR-corrected epithelial cells had identical inflammatory responses to *Pseudomonas aeruginosa* and also to purified bacterial products.

“What, then, explains the larger-than-normal inflammatory responses of CF vs. normal patients to *Pseudomonas* infections? We found a *Pseudomonas* product flagellin is a potent activator of both inflammatory signaling and also CFTR-dependent Cl secretion. We propose that this Cl secretion (along with water) is critical for flushing bacteria from the airways. In *Pseudomonas*-infected CF airways, Cl secretion and flushing of the bacteria will be missing but inflammatory signaling will be retained, so there will be neutrophil influx but no clearance of bacteria. Thus, the particular sensitivity of CF patients to these infections may result in part from the absence of CFTR’s bacterial-activated flushing function. An unusual aspect of the findings was that *Pseudomonas*-triggered cell signaling is not normally associated with the types of cell signaling that activates CFTR. Experiments in progress are attempting to determine whether CFTR is in fact activated by the bacterial products and which cell signaling pathways are involved.”

Monal Sonecha, M.D. at the University of California San Francisco presented “Clinical and Basic Research Studies of CF Airway Gland Secretions.” A summary of Dr. Sonecha’s presentation: “CF involves a defect in a protein (CFTR) present in the airway glands. Airway glands secrete mucus onto the airway surface. Gland mucus is an important component of the defense mechanism against environmental agents (e.g. bacteria) that we inhale. Gland mucus secretion is controlled by local nerve cells in the airways; the local nerve cells are controlled by local stimuli and by central nerves arising from the brain.

“The central nerves are stimulated in response to strong irritation, such as inhalation of fluid or food in the airway. They then stimulate glands to secrete through a non-cystic fibrosis protein. This causes the glands to secrete large amount of fluids and also provokes coughing as a defense mechanism to clear the airways. This kind of gland secretion is still strong in cystic fibrosis patients.

“In contrast, the local nerves are also weakly stimulated by mild irritating agents, such as inhalation of bacteria or viruses during normal breathing. We hypothesize that the response to mild local stimulation is mediated mainly or entirely by gland secretion that requires CFTR. This 24x7 gland secretion through CFTR allows normal airways to remove inhaled bacteria; thus airways are usually sterile.

“In the absence of functioning CFTR, the glands no longer respond to these local stimuli, so bacteria are able to reside in the mucus for much longer times unless they are killed and cleared with inhaled antibiotics and mechanisms to mobilize the intact gland secretion system. Our research seeks to gain control of CF glands so that their residual function can be used to help fight against airways infections.”

Vihass Visu, Ph.D. of the University of California Davis presented the study that he has just begun on Oxidative Stress in Cystic Fibrosis Respiratory Tract Secretions: Therapeutic Strategies. “The purpose of this study is to quantify oxidative processes at respiratory tract surfaces by studies of freshly obtained sputum from adult CF patients, and to assess the capacity of potentially therapeutic anti-oxidants (N-acetyl-L-cysteine [(NAC)], glutathione



[(GSH)], ascorbic acid) to modulate these processes. The results will help characterize potential benefits that might be expected to occur subsequent to therapeutic aerosol antioxidant treatments in this disorder known to be associated with oxidative stress.”



Ruth Muchekehu, Ph.D. of the University of California San Diego, presented her research on the question, “Does Poor Bicarbonate Secretion Impair Cervical Mucus Release in CF?”

“What causes the thick aggregated mucus found in mucus-producing organs affected by CF? As well as a loss in Cl⁻ conductance, bicarbonate conductance is also lost in CF. Mucins, the main component of mucus, are large negatively charged molecules that are packaged in small vesicles within cells. In order to package these large molecules in small vesicles, positively charged Ca²⁺ and H⁺ ions are required to shield the negatively charged side chains of mucins. Once released from the cell, Ca²⁺ and H⁺ need to be rapidly removed in order for mucins to expand properly and form a mucus gel layer on the cell surface.

“We propose that bicarbonate (HCO₃⁻), which readily binds to Ca²⁺ and H⁺, plays a critical role in removing this ‘shielding’ of mucins. Our hypothesis is that in CF, the failure to secrete HCO₃⁻ along with mucins, reduces the rate and degree of mucin expansion, leading to a final, thick sticky mucus associated with CF.

(Continued on page 10)

The 2007 CFRI Hall of Fame Awards

In It To Win It!

Each year CFRI proudly presents two annual awards in recognition of outstanding contributions to the CF community. As in years past, the awards are presented to a volunteer and to a CF professional, generally a medical person or researcher.

The 2007 Professional of the Year Award went to Paul Quinton, Ph.D. The Hall of Fame citation reads as follows: Paul has consistently been at the forefront of CF

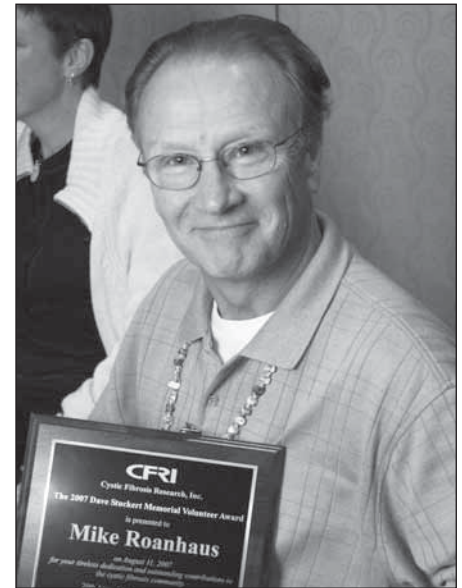


Paul Quinton, Ph.D.

research. His work has addressed the functioning of CFTR and how its various defects cause this disease. His discovery that CF is caused by the loss of a chloride channel was pivotal, impacting the directions of future research. Paul is a tireless worker behind the scenes who continually assists in focusing CFRI research.

The 2007 Dave Stuckert Memorial Volunteer of the Year Award was presented to Michael Roanhaus. The Hall of Fame citation reads: A leader in the CFRI community, Mike has served on the Board of Directors for over fourteen years. As Board President for nine of those years, he has governed with commitment and passion, helping to grow to meet the needs of a broad CF community. Mike continues to champion the mission of CFRI in many ways, promoting research, education and CF awareness.

We are blessed with the dedication of hundreds of volunteers and professionals who contribute wholeheartedly to finding a cure for CF and working to improve the quality of life for those in the CF commu-



Mike Roanhaus



nity. These two stood out particularly this year for their many, many contributions. Highlights of the Saturday awards banquet included the recognition of CFRI's Professional and Volunteer of the Year and an exciting raffle drawing.

Research Dollars (Continued from page 9)

In this state, mucins tend to be immobile and to obstruct the lumens and ducts of CF affected organs since women with CF have a reduced fertility thought to be due to thick viscous mucus, we will be using the female reproductive tract as a model to study the effects of bicarbonate on mucus release. Our study should provide a new and unique insight into the mechanism by which mucus becomes pathological in CF affected organs."

Iwona Bucior, Ph.D. of the University of California San Francisco presented her study on "Lung Mucosal Glycosylation and *Pseudomonas* Binding." Iwona is an expert in glycosylation, which is the process or result of adding sugars to proteins. Working with Drs. Joanne Engle and Keith Mostor at UCSF, experts in epithelial trafficking, she is investigating the belief that *Pseudomonas* binds to sugars on the proteins at the epithelial cell surface. The purpose of her study is to determine how altered protein glycosylation affects *Pseudomonas* binding.

10

★ *"I would encourage anyone who is touched by CF to plan on attending the conference next summer"* ★

(August 1st – 3rd).

★ —Kathy Hardy ★

Great to be Back (Continued from page 7)

informative conference. Their service is a gift to those of us who enjoy the annual gathering. Thank you to all who are involved with the planning of the conference. I would encourage everyone who is touched by CF or is interested in the lives of people with CF to plan on making their way to Redwood City next summer for the conference (August 1st - 3rd). And if you aren't able to attend, I encourage you to purchase DVD's of the lectures so you can stay informed. I look forward to meeting some of you next August.

(Note: all conference CD's and DVD's are available for a nominal shipping/handling fee. See info on page 14.)



Commemorating the Launch of California's New Born Screening Program

In It To Win It!



Each of the people pictured here had a major role in California's SB1748 which led to the state's launch of newborn screening of CF on July 16, 2007. Our next *CFRI News* will present some statistics for the first few months of the program.

Pictured left to right), and surrounding our Executive Director, Carroll Jenkins, are: Sherri Sager, Chief Government Relations Officer, Lucile Packard Children's Hospital; Catherine Comacho, Deputy Director, Center for Family Health, California Dept. of Public Health; Marty Kharrazi, Ph.D., Chief, Program Research and Demonstration Section, Genetic Disease Screening Program, California Dept. of Public Health;

Liz Figueroa, author of Senate Bill 1748; Christy Quinlan, Deputy Director, Information Technology Services, California Dept. of Health Care Services; Ajit Bhandai, Ph.D., Acting Chief, Genetic Disease Lab, Genetic Disease Screening Program, California Dept. of Health; and Fred Lorey, Ph.D., Acting Chief, Genetic Disease Screening Program, California Dept. of Health.

Starlight Hospitality

Other Groups Provide
Information to Attendees



Other CF non-profits are drawn from across the nation to participate in our conference. Many then choose to use our conference to conduct their own meetings surrounding our program, and reach others with common interests.

Terry Nelson again headed up a volunteer group that decorated and set-up our Starlight Hospitality Suite. CFRI extends

a warm welcome to these collaborative CF groups: Boomer Esiason Foundation, Elizabeth Nash Foundation, and CF Lifestyle Foundation. Other groups who shared information included: California Public Health Institute, the United States Adult Cystic Fibrosis Association, Genetically Handicapped Persons Program (GHPP), Breathing Room, Peter Judge Legacy, CysticFibrosis.com, 6500 Red Roses, and The Diabetes Society.

Raffle prizes were displayed along with our "Gallery of Stars": photos of people with CF describing something about their interests, displayed on colored star cut-outs.

Our CFRI Conference attendees came away with medical literature and information they will use to improve the quality of their lives.

In It To Win It!



Andrew Byrnes
Conference Emcee



Alisa Evans and
Ashley Duerr



Linda Burks, Karen Maschino, Sandy Schumacher and Siri Vaeth-Dunn



Laura Tillman



At the Saturday dinner, attendees enjoyed their choice of two "starters" prior to receiving their choice of several entrees. All food for the three days was served by a gloved wait staff to assist in preventing cross-infection.



Jim, Ann & Carolyn Nash attended the conference.



Michelle Compton with her mom, Diana and Paul Russell at Friday's kick-off reception.



Ajit Bhandai, Ph.D.



Liz Figueroa



Fred Lorey, Ph.D.



Catherine Comacho



Marty Kharrazi, Ph.D.



(See previous page for story on honored guests.)

In It To Win It!



Kathryn Boyle, RN



Jeanne Barnett



Manuel Naku



Ann Steiner, Ph.D.



Bryan Lask, M.D.



David Cone



CFRI members provided a broad perspective on raising children with CF to adulthood. These experienced parents offered their suggestions and answered far-ranging questions from attendees. From (left to right) Ann Robinson (moderator), Lorin Fink, Siri Vaeth-Dunn, Randy Evans, Kathleen Flynn and Leon Borowski.



Robin Modlin and her daughter Anna share a joyous moment during the conference.



One of fifty "stars" shown in the Starlight Hospitality Suite is Timmy "The Brick" Nelson and his parents.



Re-elected at our recent membership meeting, CFRI's Board of Director officers attended the conference; pictured here: Bradley Baugh, Esq., VP, and JoAnn Davis, President.



Elyn Silverman



Randy Evans



Kathy Russell (left) moderates "Ask the Experts" panel discussion with James Yankaskas, M.D., Joan Germana, M.D., and Jeffrey Wine, Ph.D.



Paul Feld



Kathy Russell

CFRI 2007 Education Conference — DVD's / CD's

Thanks to our community of volunteers, CFRI presents the 2007 Education Conference in DVD and audio CD-ROM formats. Special 2-Disk sets containing ALL presentations are available: \$20 for a 2-Disk DVD set; \$2 for a 2-Disk CD set. (The 2-Disk DVD set contains a few glitches that do not affect the quality of the presentations.) Individual presentations are also available: \$3.50 per DVD or \$35 for an entire set of individual DVD's; \$1 per CD or \$13 for an entire set of individual CD's.

To place your order, please complete this form and provide us with your information by mail, fax, or phone: *Cystic Fibrosis Research, Inc., 2672 Bayside Parkway, Suite 520, Mountain View, CA 94043, USA, Fax: (650) 404-9981, Phone: (650) 404-9975.*

Title/Speaker(s)	Qty.	Time (Approx.)	Item Code#	DVD	CD
Special 2-Disk set Contains ALL presentations (listed below)	2	11 hrs. 30 mins.	00	<input type="checkbox"/>	<input type="checkbox"/>
"CF Research Working for a Better Quality of Life" Carroll Jenkins, Executive Director, CFRI Marybeth Howard, Ph.D., John Widdicombe, Ph.D.	1	47 mins.	1	<input type="checkbox"/>	<input type="checkbox"/>
"CF Research" and "In It to Win It" Daniel Hassett, Ph.D. "Killing Bugs with Sodium Nitrite" USACFA "In It To Win It – Living Proof"	1	56 mins.	2	<input type="checkbox"/>	<input type="checkbox"/>
"Clinical Treatment of CF: What's New, What's Next?" James Yankaskas, M.D.	1	53 mins.	3	<input type="checkbox"/>	<input type="checkbox"/>
"Developing Healthy Eating Strategies for Those with CF" Bryan Lask, M.D.	1	46 mins.	4	<input type="checkbox"/>	<input type="checkbox"/>
"Advocating for the Best CF Care" Joan Germana, M.D.	1	60 mins.	5	<input type="checkbox"/>	<input type="checkbox"/>
"Parents Living with Cystic Fibrosis" Panel Discussion Leon Borowski, Randy Evans, Lorin Fink, Kathleen Flynn, Siri Vaeth-Dunn, Ann Robinson (Moderator)	2	3 hours	6A 6B	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
"Basic CF Research – Two Diseases with One Name: Dual Tracks to Drug Discovery" Jeffrey Wine, Ph.D.	1	1 hr. 5 mins.	7	<input type="checkbox"/>	<input type="checkbox"/>
"Financial Planning & Special Needs Trusts" Jason Papier, PW Wealth Management Michael Gilfix, Esq., Gilfix & La Poll Associates	1	57 mins.	8	<input type="checkbox"/>	<input type="checkbox"/>
"Health Insurance Assistance for CF" Lisa Yourman, Health Insurance Broker and Director, New Jersey Health Insurance Board <i>This disk includes the "Financial Planning, Special Needs Trusts & Health Insurance Assistance for CF" Panel Discussion</i>	1	1 hr. 5 mins.	9	<input type="checkbox"/>	<input type="checkbox"/>
"Effective Strategies for Working with Your School System" Lisa Yourman, CF Parent and Patient Advocate	1	58 mins.	10	<input type="checkbox"/>	<input type="checkbox"/>
"Ask the Experts" Panel Discussion Joan Germana, M.D., Jeffrey Wine, Ph.D., James Yankaskas, M.D., Kathy Russell (Moderator)	2	1 hr. 30 mins.	11A 11B	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>

Name _____

Address _____ City _____ State _____ ZIP _____

Phone _____ Email _____

Total Qty: DVD's _____ CD's _____ Payment Method: Check Credit Cash Total Amount \$ _____

Credit Card Type / Number _____ Expiration Date _____

Signature _____ CF Relation: _____

CF Teen & Adult Day Retreat

Staying Alive: '70's Disco

By Anna Modlin

This year's CFRI Teen & Adult Day Retreat, **Staying Alive: 1970's**

Disco, was sensational. We had 28 full time attendees, and 14 visitors throughout the week with an age range from 18 to a 50 year old CFer. What an amazing range of experience and knowledge that everyone brings to retreat! We had guest speakers including Dr. John Mark from Stanford who spoke about alternative medicine choices. A dietician, Karen Rubio spoke about CFRD (CF related diabetes), and Ariana Candell, MFT, led a dance therapy class.



Two day retreaters plant the maple as others watch.

In honor of the 1970's theme, we had an evening disco and great aerobic exercise. A special event of the Retreat was a roller skating rink excursion, enjoyed by all. We were given the opportunity to plant a Japanese maple at the Vallombrosa conference center that was also celebrating their 60th anniversary. We planted the tree in honor of all of those who have lost their lives to CF. A beautiful planting ceremony was held and all of the retreat attendees had the opportunity to participate.

As the week came to a close, we had an awards ceremony and talent show that, as always, brings joy and laughter throughout the night. The end of retreat always comes too quickly, however the bonds and close connections that people make throughout the week last through the years. Our combined hope to return to future retreats gives all attendees, CF and non-CF, the strength to get through another year.



Monica Koller, Maggie Sheehan and Sonya Haggett work on crafts.

Stories, Tears, Joy & Laughter

A Japanese maple tree was planted at the August CFRI retreat to honor those who have since passed. Candles were lit and stories told about dearly departed loved ones.

Reflect on the bravery of retreat participants; their ability to tell stories and remember friends who had been in their midst in years past. I confess it was emotionally difficult to listen. How much more difficult to participate?



I marvel at their ability to laugh, shed tears, while remembering joyful times with friends.

Retreat is a magical time to share with others what participants go through and learn daily about the realities of living with CF.

—Darrell Batchelder

Spreading CF Awareness and Education



A talk with Roy Avila of Action 36 Cable 6 (KICU-TV), San Jose, California. This interview spread awareness of cystic fibrosis to the community, as the Interact Club, Los Altos Sunset Rotary and the Golden State Road Warriors teamed up with CFRI recently for a Wheel Chair Basketball exhibition game.



Interview participants included Carroll Jenkins, Executive Director of CFRI and Giulia Siccardo, President of the Interact Club of Pinewood School in Los Altos.



(left to right) Our CFRI Executive Director, Carroll Jenkins, Board member, Mike Roanhaus and Isa Stenzel Byrnes share information about cystic fibrosis and CFRI's mission with listeners on KKUP/ FM radio, Wednesday morning, September 19th. The one-hour show included questions from program callers, and answers were provided by our team. The show was hosted by Jim McMillen from KKUP (behind microphone).



Spreading the word on CF to the Community



CFRI's Director of Programs and Operations, David Soohoo, puts the finishing touches on our display. He spent a September weekend at the San Jose "Living Well Expo," a community outreach health program sponsored by NBC, Channels 11 and T48, Telemundo. Over 100 health organizations lent their expertise with health screening and educational programs to what fair organizers characterized as more than 30,000 attendees over the two-day event. This effort is one part of CFRI's commitment to community outreach.

Peter Judge CF Counseling Program

An Investment In Improving The Quality Of Life

Health care for those with cystic fibrosis reaches a new dimension through the Peter Judge Legacy Program (PJLP) because the program includes the care of body, mind, and spirit and at the same time, care for those with CF, their parents, siblings, children, and their care givers: doctors, nurses, respiratory therapists, etc. In short, as benefactor, Julie Judge said, "If you can make a difference to even one part of the

CF network, you improve the well-being of all."

Peter Judge died of CF at 42. The PJLP was created to recognize the hospital staff at Stanford for their expertise and compassion. With guidance from Art Johnson at the Stanford Center for Education in Family & Community Medicine, the program

has been designed to improve the quality of life for those affected by CF. The result is the Peter Judge CF Counseling Program at the neighboring Institute of Transpersonal Psychology (ITP). Four interns will offer counseling to the CF community on a sliding scale basis. Said program director Jessica Herbold, Ph.D., "No one will be turned away on the basis of financial need."

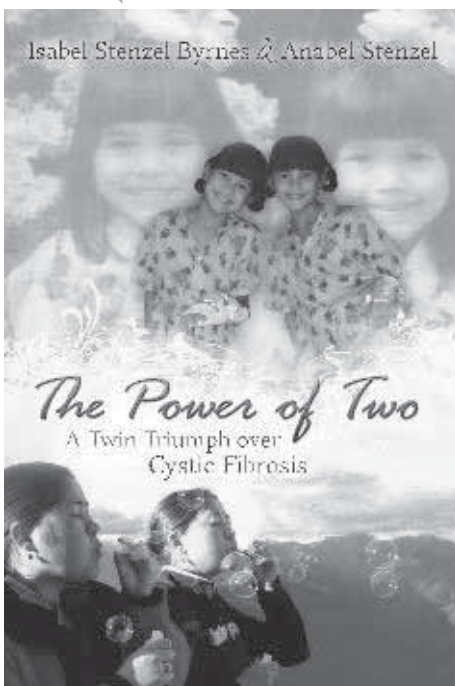
Pictured here (L to R, standing) CFRI's Executive Director, Carroll Jenkins (Training Moderator); Jessica Herbold, Ph.D.; Art Johnson, Ph.D.; Isa Stenzel Byrnes and Ann Robinson.



Art and Isa demonstrate through a humorous skit, how to avoid cross-contamination with precautions and following the "three-foot" rule.

On September 26th, CFRI conducted the first in a series of training sessions to orient interns and counselors to the needs of the CF community.

For additional information contact Jessica at 650-493-4430 JHerbold@ITP.edu



The Power of Two—

*Introducing a new book written by
Isabel Stenzel Byrnes & Anabel Stenzel*

Former Vermont Governor, Dr. Howard Dean, gave *The Power of Two, A Twin Triumph Over Cystic Fibrosis*, the following quote: "This miraculous story of twin sisters who grew up with cystic fibrosis is gripping and uplifting. It is a chronicle of modern medicine, in terms both of heroic surgery and of the less glamorous, but ultimately more important tedium of daily chronic care. There are thousands and thousands of Americans with cystic fibrosis. This is mandatory reading for them and their families..."

Frank Deford, Author of *Alex: The Life of a Child* about his daughter with CF, said: "Isabel and Anabel's memoir of their

extraordinary battle with cystic fibrosis is at once uplifting and frightening, touching and tough, but always powerful and filled with life and spirit, alike. It is a story that we all must be moved by, grateful that these two sisters shared their agony and love with us."

Their book may be ordered through the University of Missouri Press at: www.press.umsystem.edu – also credit card customers can call toll free 1-800-828-1894. The book is also available online at Amazon, Barnes & Noble, etc., or through your local book store. The retail price is \$29.95 plus shipping/handling.



NEXT ISSUE



Makinnon Baugh

• CFRI and other local charities participated in front of 300+ spectators against the Golden State Road Warriors, a wheelchair basketball game. Star Makinnon Baugh plays for CFRI.

• What's happening since the implementation of California's new born screening program? Our next issue will share statistics and results from the first months of the program.

• GHPP– State representatives from California's Genetically Handicapped Persons Program (GHPP) gave a presentation and answered questions at our recent October membership meeting. Our next CFRI News will share many of the details. Much of this new information, including application forms, is now available on their web site: www.dhcs.ca.gov/services/ghpp/Pages/default.aspx.

CF Researcher Receives Presidential Medal of Freedom

The co-discoverer of the CF gene, Dr. Francis S. Collins, received the Presidential Medal of Freedom, the Nation's highest civil award, on November 5th. Dr. Collins is Director of the National Human Genome Research Institute and is best known for his leadership of the Human Genome Project. He received this prestigious award for his revolutionary work in biomedical research. In 1989 Dr. Collins identified the defective CF gene and its protein product (CFTR) which allows other researchers to understand CF at a basic level. It was a momentous milestone in the effort to find a cure and most research since benefited from this work.



Rebecca Burks

Three Day Conference (Continued from page 1)

Sofitel staff worked closely with CFRI and USACFA to maintain effective cross-infection control.

One attendee said, *"This is my fourth year attending and each year I learn something new. I stayed though the end of the day Sunday and personally found the "Ask the Experts" panel discussion very beneficial. The networking and social aspects of the conference is especially enjoyable too."*

Because of the generous support of our sponsors, the cost to attend our conference is very reasonable. Scholarships are also available. Mark your calendars for CFRI's next Conference to be held August 1-3, 2008 at Sofitel San Francisco Bay.

CF Links

United States Adult Cystic Fibrosis Association provides a newsletter called the CF Roundtable. The cost of the newsletter is very reasonable. Learn more at: www.cfroundtable.com



Cystic Fibrosis Lifestyle Foundation 802-310-5983 or email: clifestylefdn@yahoo.com The goal of this foundation is to help adolescents and young adults with opportunities that are both therapeutic and fun. They fund recreational activities.

CysticFibrosis.com is a leading online health resource focused on support, education and hope. At our recent conference they videotaped participants as a way to connect them to their 6,500 CF patient members. Topics discussed include research, medical findings, transplants, genetic mutations as well as support and coping techniques. To view the videos visit www.Cystic-Fibrosis.com



142 Golfers Swinging For CFRI Charities



Our 23rd annual CFRI Golf Tournament on August 6th, 2007 raised over \$57,000 for research. CFRI Board Member and Tournament Director Scott Hoyt coordinated a host of volunteers at Cinnabar Hills Golf Course, where he is the Head Professional. Planning, marketing and delivering a great event was shared by the Tournament Committee headed by Scott, Ralph Swanson, Michael Roanhaus, Francine Bion, Tina Capwell and Dea Roanhaus.

Our next tournament is scheduled for Monday, August 4th 2008. Mark your calendars!

A Great New CFRI Benefit – Join Our Wine Club!

Readers of this newsletter may visit our web site and 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.

Go to:
www.CFRIWineClub.com
Questions? 650-404-9978



CFRI

Cystic Fibrosis Research, Inc.
33 Years of Research, Education & Support

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.

Enjoy quality, affordable Central Coast premium wines while saving up to 30% and the winery sends us an additional 15% to support our mission.

There's more! Free delivery in the S.F. Bay Area on case lots. Smaller orders of three or six bottles incur a small shipping/handling fee. You must be 21 to order and accept wine. Credit card orders are processed and delivery is generally within three business days www.CFRIWineClub.com Check us out and order via the "Order" tab at the top of our page.



In Honor of (From June 1, 2007 to August 31, 2007)

Parents of young people with CF

The Altano Family
 The Baugh Family
 The Byrnes Family
 The Burroni Family
 The Charles Nelson Family
 The Flynn Family
 The Flynn/Wakefield Family
 The Hardy Family
 The McMullen Family
 The Stenzel Family
 The Thibault Family

Chelsa About
 Claire Alexander
 Adam Aliotti
 Gianna Rose Altano
 Sadie Anderson
 Rebecca Atkins
 Jamie Baker
 Kyle Baker
 Lucy Barnes
 Makinnon Baugh
 Marin Baugh
 Maggie-Faye Bendz
 Brett Bennett
 Kitsy Bennett
 Amanda Bergman
 Allison Best
 Aidan Biggar
 Oliver Biggar
 Allyson Bond
 Diana Brady
 Monica Brown
 Brian Burks
 Linda Burks
 Isa Stenzel Byrnes
 John Robert Christie
 Lauren Colonna
 Eliza Colten
 Cameron Cornell
 Laura Cryan Zellmer
 Barbara Curry
 Margaret Rosenfeld
 Gayle Davis
 Michelle Davis

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

Gordon DeVore
 Dr. Austin Schellinck
 Tess Dunn
 Kristen Favero
 Jarrod Fischer
 Kathleen Flynn
 Jacob Fraker
 Joseph Fraker
 Emily Fredrick
 Jessica Fredrick
 Natasha Gaziano
 Mark Ellis Gerow
 Elyse Elconin-Goldberg
 Jennifer Goodwin
 Barbara Greenberg
 Sonya Haggett
 Alex Hampton
 Lizzy Hampton
 Glenna Hannibal
 David Hardy
 McKenna Hardy
 TJ Hardy
 Kerry Harrison
 Abbey Heilman
 Max Heilman
 Anthony Hidalgo
 Drew Hotson
 Dalton Huston
 Alex Jenkins

Lindsey Nicole Jensen
 Laine Jones
 Michelle Jones
 Peggy Bort Jones
 Julia Judge
 Jeremy Kharrazi
 Lori Kipp
 Bridget Klein
 Eleanor Kolchin
 Kathy Koomjian
 Rick Koomjian
 Michael Kozlowski
 Renee Kozlowski
 Eve Lamond
 Don Lamond
 Nancy Lane
 Kody Lawrence
 Lori Lawrence
 Michael Livingston
 Rose Logue
 Alyson Lowery
 David S. Martin
 Jean Mathews
 Claire McCabe
 Rachel McMullen
 Rebecca McMullen
 Carly McReynolds
 Parry Mercer
 Jackie Merrill

Kelly Miller
 Anna Modlin
 Jessica Muncie
 Jessica Nett
 Alan Osur
 Lisa Osur
 Dellene Ott
 Steven Peterson
 Erin Phillips Taylor
 Robyn Primack
 Briauna Red
 Rebecca Roanhaus
 Carl Robinson
 Ethelyn Robison
 Cortney Roeder
 Andrew Sabatino
 Katelyn Salmont
 Corey Sarkis
 Beth Schenck
 William Schenck
 Kacey Schumacher
 Myranda Selvage
 Janice Shaul
 Joe Sinnaeve
 Matt Spadia
 Ethan Spain
 Megan Stacy
 Lisa Steiding
 Ana Stenzel
 Dr. Ashley Streter
 Brian Tacke
 Heidi Tegner
 Adam Thompson
 Mary Tripp
 Todd Trisch
 Mat Vitousek
 Daniel Vogel
 Robert Vogel
 Devin Wakefield
 Jake Ward
 Kassi Watkins
 Clare Mathews Webster
 Harold Weight
 Peggy Weight
 Dan Weld

In Memory of (From June 1, 2007 to August 31, 2007)



“In Memory of” is a donation made in the name of a deceased person.

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

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

Send name of the deceased, the name and address, city/state, zip of the relative/spouse, etc. that you would like acknowledged a donation was made. Send to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043.

The Thibault Children

Kim Adelman
Barbara Stone Baird
Jennie Louise Bartolomucci
Mark Belcher
Charley Borreani
Greg Brazil
Kyle Butler
Kerry Canavan
Roger Carroll
Scott Chalfant
Sonya Chartrand
Cindy Clark
Ryan Coelho
Karen Collins
Spencer Compton
Desiree Contreras
Claire Cresci
Rachel Crocker
Sam Curtin
Charlie Delgado
Beverly Detrick
Marty Detrick
Marvin Detrick
Neva DeVore
Janice Gregory Lando
Donn Lando
Don Egli
Boyd Faulk
Pam Faulk

Christina Fichter
Erby George
Diana Goodman
Rose Goodman
Cindy Haley
Hayley Horn
Leslie Hotson
Kathy Judge
Peter Judge
Mildred La Rue
Gertrude Livingston
Olga Lombardi
Dawn Longero
Philip W. Loux
Stephanie MacArthur
Bob Mackey
Lucy Marsh
Paul Mathews
David McAfee
Margaret “Peg” McFadden
Mr. and Mrs. Ken Miller
Brian Moore
Michael Moore
Robert Moore
Eugene Morris
Kim Nelson Piscitello
Scott Nelson
Judy Nelson Aspromonte
Michele Denise Olson
Jennifer Ortman

Darla Osburn
Sean Peterson
Jeremy Pfau
Mae Plemmons
Jon Prater
Tim Prater
Diane Queen
John Rocha
Pamela Rockhold
John Runge
Maureen Sazio
Jeremy Selvage
Paul Shefchek
Arthur Simpson
Tammy Smerber
Della Mae Smith
David Stuckert
Laurie Stuckert
Kevin Swiggleton
Harold A. Tegner
Dresden Tingley
John Trask
Phyllis Tripp
Frank Turner
Freda Turner
Jennifer Uskoski
Haley C. Wester
Henry P. Wester
Pete Wilson

CFRI Day Retreat 2007: Honoring those who have passed



Help Us Grow - Donate to CFRI

Your Donations Support Vital CF Research and Education

CFRI Receives Coveted 4-star Rating from Charity Navigator



CFRI achieved a coveted 4-star rating for sound fiscal management from **Charity Navigator**, the nation's premier charity evaluator in providing donors with essential information needed to give greater confidence in their charitable choices. Only one in four charities today is qualified to receive four stars. **Charity Navigator** has been profiled and celebrated for their unique method of applying data-driven analysis to the charitable sector by *The New York Times*, *NPR* and *The Chronicle of Philanthropy*. CFRI is also listed in **www.GuideStar.com**, another web site that ranks charities on their financial health, stability and dedication to their cause.

Become a Member

CFRI depends on its membership to help meet the needs of the cystic fibrosis community. As a member, you will have an active voice in the organization's

delivery of services. A large and active membership is key to CFRI's organizational health and responsiveness. Annual dues are just \$25.

Mothers' Day Tea

Every year, the Mothers' Day Tea continues to be our largest fundraiser. With the assistance of our volunteers, tea senders and donors, generous contributions are directed to research, education and support. If you would like to be a "tea sender" for our virtual tea in 2008, please call 650-404-9975 or email cfri@cfri.org.

In Honor of, In Memory of

Any gift given can be made in honor or in memory of a loved one. Their name will appear in our newsletter, and an acknowledgement will be sent to the person honored or to their family. Many choose to send in a group contribution to celebrate occasions such as birthdays.

Giving Stock

Giving a gift of appreciated stock to Cystic Fibrosis Research, Inc. (CFRI) is easy and can be rewarding in several ways. You

will not have to pay capital gains tax on stock that has appreciated over the years. You will receive an income tax charitable deduction for the full-fair-market value of the stock on the date of the gift, and your stock gift will make possible our research and educational programs that are helping everyone face the challenges of cystic fibrosis. If you hold stock certificates that you wish to donate, we will put you in touch with our contact at Smith Barney, Inc., for complete instructions. Please call 650-404-9975.

Life Settlements & Planned Giving

Planned giving offers benefits for donors that often include increased income and substantial tax savings. Life Settlements, and the donation of your life insurance policy if you no longer need it, may also be to your advantage and benefit CFRI. Both events create the opportunity to meet your philanthropic goals and provide positive tax benefits. Please contact us for information: 650-404-9977.

CFRI Golf

At this year's CFRI Tournament, golfers spent a rewarding day at the course and were treated to a fantastic dinner and auction in the evening, all to support cystic fibrosis research! Next year's tournament will be held again at Cinnabar Hills Golf Club in San Jose, California, on Monday, August 4, 2008. If you're interested please contact Scott Hoyt 408-323-7803, shoyt@cinnabarhills.com.

Vehicle Donations

For many years CFRI has received donations of vehicles. If you have a used car, boat, recreational vehicle or motorcycle and would like to support CFRI research and education, please consider donating to CFRI. This contribution is tax-deductible and we will coordinate the transfer of property and handle the paperwork.

December 31st, 2007 Ends Special Tax Advantage For IRA Contributions

If you've reached age 70 and a half, you have a special opportunity to make gifts of up to \$100,000 per year to any public charity. Individuals making a donation (directly from their IRAs or Roth IRAs) will be allowed to exclude this distribution from gross income; however, the gift itself cannot be treated as a charitable deduction. These gifts will count towards the required minimum distribution for the year and are offered only for years 2006-2007.

Restrictions include: You must be 70 and a half years or older; make the contribution to a public charity directly from your IRA, for no more than \$100,000 by Dec. 31st, 2007; and retain your gift receipt for tax purposes.

PLEASE NOTE: CFRI is *NOT* providing professional tax advice. Please consult your tax advisor before proceeding with a gift under the Pension Protection Act.

An Art Contest for the CF Community

– *Send us your “Tea Art!”*

We invite YOU to submit your artwork for our

2008 Mothers' Day Tea invitation

Your artwork must have a clear reference to Tea! This contest is for those of any age who have CF. Please send your contact information (name, address, phone number) along with your art. Bright colors with good contrast will copy best in an invitation.

Final decision of art to be used as the 2008 Tea invitation will be decided by the MDT Committee.

Please send a copy of your piece by e-mail (jpg) to cjenkins@cfri.org, or a color photocopy – **no originals please** – to CFRI Tea Art, 2762 Bayshore Parkway, Suite 520, Mountain View, CA 94043

Questions? E-mail CJenkins@CFRI.org or call 650-404-9977.

All entries must be received by December 17, 2008

I look forward to hearing from you!

Carroll Jenkins

Mothers' Day Tea 2008

Just clip and send us this order form, call in your order 650-404-9975 or email us: cfri@cfri.org. We will provide you with invitations and envelopes, literature on CF, and delicious Tea, generously donated by R.C. Bigelow®.

You send these to family and friends, and join others across the country for a

satisfying cup of tea. Contributions from the Tea are sent to us in envelopes provided. It's that easy. With your support, we fund important research and supply current CF information to those with cystic fibrosis and their families. All tea invitation senders entered into a teapot raffle. The winner will be chosen on March 14, 2008.



Thank You!

Mothers' Day Tea 2008 !

Yes, I would like to send Tea invitations. Please send _____ (number of invitations)

Your Name (please PRINT)

()
(area code) telephone number

PO Box/Street Address

City/State/Zip

Email Address

Relationship to CF

Our 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.

Get to know us:

www.cfri.org
650.404.9975

CFRI: a 501(c) (3)
non-profit organization,
Federal ID# 51-0169988

Reach Staff Directly

Carroll Jenkins	(650) 404-9977	cjenkins@cfri.org
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Mary Convento	(650) 404-9975	mconvento@cfri.org
Darrell Batchelder	(650) 404-9978	dbatchelder@cfri.org
Information	(650) 404-9975	cfri@cfri.org



Elena, Darrell, Mary and David at the CF Conference in August.

Our 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.

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



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

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