



# CFRI news

33 Years of Research, Education & Support

## Should You Consider a Special Needs Trust?

By Darrell Batchelder

As life expectancy continues to improve, parents in the twenty-first century may be the first to die *before* their CF offspring. Over the last forty years, the average age for someone with CF has gone from eleven to thirty-seven years. With improved treatments and medications, with ongoing research and testing on the clinical side, with better trained CF Centers held to high peer review, some doctors are predicting almost a “full” life expectancy for many CF patients in the twenty-first century.

Most CF adults will thus establish an independent work life. Possible future disability due to the progression of CF will be covered by Social Security Disability Insurance, SSDI benefits after only a few years of paying into the system. Under current law, benefits will include monthly payments for life and Medicaid. There will also be CF adults who may never be able to work and thus may have to be supported through Social Security Income, SSI. It is these CF children that we must

be concerned about when considering a SNT and planning our estates so that they can continue to receive benefits.

Attorney Michael Gilfix in Palo Alto specializes in this area and says, “Leaving money in an Estate Plan will not automatically care for a special needs relative.” Most disabled individuals who receive, or might receive monies in the future from SSI and Medicaid, are those protected by an SNT.

### Why Need It?

Here’s what Kevin Urbatsch, Esq., had to say in a recent paper he wrote on this

subject: “Both SSI and Medi-Cal are only available to the poor. Persons who are eligible for SSI benefits are automatically eligible for Medi-Cal. Persons not eligible for SSI benefits may be eligible for Medi-Cal through other programs (e.g., if they are “medically needy”). **If a person receives SSI or Medi-Cal benefits while ineligible for them, the benefits received must be repaid.** In addition, if disqualified, an individual must apply again to reestablish benefits. The process is complex and time consuming.”

The primary tool for estate planning to benefit persons with a disability who receives SSI is a specialized SNT. A well

(Continued on Page 13)

### Spring Update

## RESEARCH

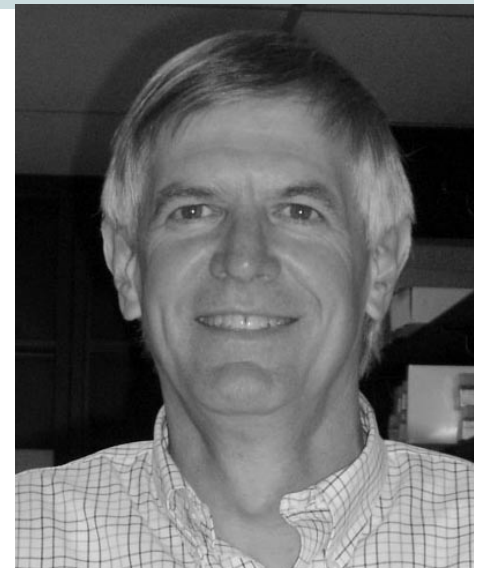
Your CFRI Dollars at Work

## CF Affects the Liver Too—

By Charles Falany, Ph.D.

Cystic fibrosis (CF) is a disease that affects many tissues and organ systems. Although the major pathology of CF involves the lungs, problems with the function of the pancreas, intestinal tract, reproductive organs and liver also require research and treatment. As the lifespan of CF patients has improved due to advances in the therapy of lung disease, treating other aspects of CF is becoming more important to continue to extend survival and improve the quality of life.

To better understand the liver problems associated with CF, my team at the University of Alabama at Birmingham is study-



Charles Falany, Ph.D., at his laboratory at the University of Alabama in Birmingham. His research is sponsored by CFRI through the New Horizons Research Campaign.

ing the effects of the loss of cystic fibrosis transmembrane receptor (CFTR) function in the liver on the regulation of biochemi-

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**CFRI NEWS**  
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# Notes from Our Executive Director

I am so pleased to give you an update on our activities at CFRI!

You know that CF is no longer just a childhood disease. In fact, over the last thirty-five years the average age of someone with CF has increased by more than twenty-five years. Today, many CF teens are entering adulthood, leaving home for the first time, and coping with CF. A Special Needs Trust may be important to consider at this time. Robin Modlin begins a discussion of transition to college on page 3.

We are currently funding seven CF research projects. Thanks to our Research Advisory Board, steering committee and other reviewers who have donated their time to ensure programs of the highest quality.

Three researchers supported through our New Horizons Research Campaign will finish their two-year projects this summer. We look forward to their reports after completion of their projects and to a new round of this funding in the fall. We also sponsor four post-doctoral fellows, who are now in their first year of research through our Elizabeth Nash Memorial Fellowship program. See page 12 for a listing of these projects.

California Newborn Screening for CF is making a difference in the lives of newly diagnosed infants, their parents and in several cases, their

siblings. Our Newborn Screening article on pages 10-11 brings you up to date.

Our 21<sup>st</sup> Annual Education Conference will be held August 1-3 at Sofitel San Francisco Bay. Join us! You will find our list of speakers on page 5 and an invitation to our annual Adult & Teen Day Retreat on page 16. The attendance fees for both are kept to a minimum – the result of many generous sponsors who support these events. Thanks to them and to volunteers from far and near.

Enjoy a new column highlighting the contributions of our founders: we begin with an interview of Maxine Eggerth on page 7.

Spring is Mothers' Day Tea time. Almost three hundred volunteers donate time to send thousands of invitations asking for your support. It's not too late to sign up to send (or receive) our Bigelow Perfect Peach Tea!

Warmly,



Carroll Jenkins  
 Executive Director  
 650-404-9977  
[cjenkins@cfri.org](mailto:cjenkins@cfri.org)



## Calendar of Events

### Wednesday, May 28, 2008 CFRI'S GENERAL MEMBERSHIP MEETING: Michael Gilfix, Esq.

*Should you Consider a Special Needs Trust?;* Lucile Packard Childrens' Hospital, Stanford, CA  
 (See story on page 9)

### April-June, 2008 ON-GOING MOTHERS' DAY TEA EVENTS

### August 1-3, 2008 CFRI'S 21<sup>ST</sup> ANNUAL EDUCATION CONFERENCE

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

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

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

### August 4, 2008 CFRI GOLF TOURNAMENT

[www.cfri.org](http://www.cfri.org)

## TRANSITIONS—

# Going to College?

By Robin Modlin

**F**rom a parent's perspective, one of the important tasks of the teen years is deciding what to do after high school. This decision is determined by your child's interests, abilities and health status. While not all want to go to college, if your child has decided to attend, it can be an important part of his/her transition in becoming independent and responsible. It is easy to overlook opportunities or make mistakes during this transition. This is a time of learning and letting go.

How can we as parents be realistic about the limitations of CF and supportive of our child's hopes of an adult life? Being realistic is knowing all the plans and dreams could change. Being hopeful is living fully. Today is all we know. What better way to spend a young adult life than learning and living with other young people?

One of the best ways to navigate this period is to use important parenting skills and tools. Tools such as honesty, communication, and forgiveness are crucial to parenting a CF child. Honesty is seeing what is right in front of you and knowing the challenges you meet as a family. Communication includes educating yourself and your child about these individual challenges and how they impact every family member. Forgiveness includes acceptance and realizing there is no single right answer.

If you and your child feel ready, and begin to consider a college, there will be questions such as: where is your child going to live? This is probably your most crucial concern. Second, will they get the support needed to be successful? What if your student gets sick for an extended period? What will happen?

Many families address these concerns by establishing a relationship with the Disability Resource Center on campus. Through this center the college student's

special needs and concerns can be met. Find out about the DRC on your child's campus before he or she registers. You will need a letter from your physician describing health status and special needs before qualifying for services. Through this resource your child may be able to have a single dorm room, special bathroom privileges, a note taker in class and other accommodations. These services are provided by law *but they require you and your student to ask for them.*

There are also special scholarships for CF patients available through **Solvay Pharmaceuticals, The Cystic Fibrosis Scholarship Foundation, The Willard Bernbaum Scholarship Fund, The Boomer Esiason Foundation** and other sources. Consult your local CF Center about financial opportunities. In addition, research your state's Department of Vocational Rehabilitation. In the state of California, CF patients may qualify for financial coverage of a portion of their tuition while attending college, as well as supplies, books and other expenses. This is determined by health status and not necessarily financial need. Investigate if this is available in the area your child will be attending school. (They may qualify after the first year of residency if they've moved to that state or are living with a relative in another state while attending school.)

Other things to consider:

- Find a pharmacy near your student.
- Find a local physician that's familiar with CF.



Doug and Robin's daughter Anna graduated in 2007 with a Master's Degree from Santa Clara University.

- Ask your medical providers if you should update any of your medical equipment.

- Investigate if your child can have access to a kitchen to cook or store extra food. Many students take a small refrigerator and microwave for their dorm rooms.

One of the benefits of your children going to college may include seeing them develop a new found self-confidence and openness about CF while knowing they can take responsibility for themselves. Another benefit will be practice in "letting go" while you pass on the handling of this disease to them. This is crucial to their success as an adult with CF.

The task of parenting children with CF requires a special nurturing and diligence. It can be difficult to let go. Not to take the place of your child, but to help yourself during this transition, find a focus. Pursue a new hobby or delve deeply into a personal interest you didn't have time for previously; perhaps attend a college class yourself (but not the same class as your child!).

Seeing your child grow, get a job, or go off to college fosters feelings of pride and hope. Give yourself credit for your hard work and success.

## BOOK REVIEWS:

## Sick Girl Speaks

by Tiffany Christensen

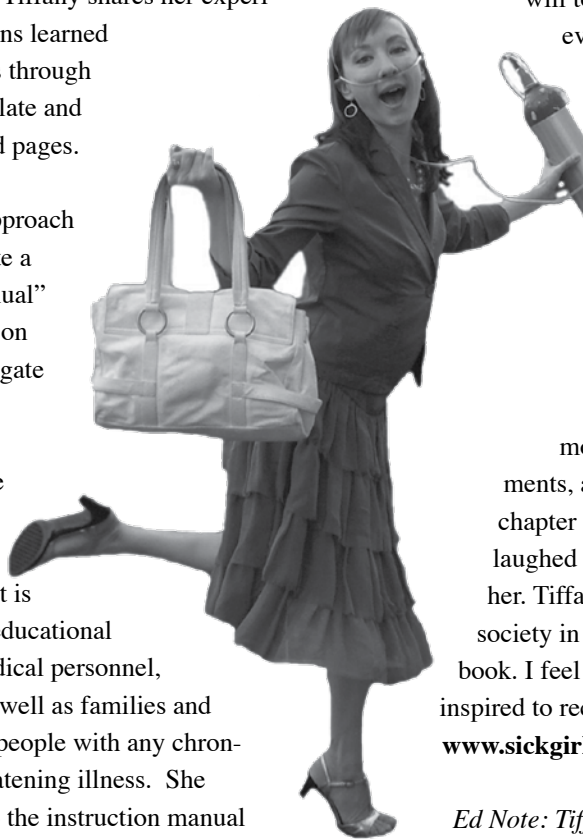
Reviewed by Anabel Stenzel

This book is thought provoking and informative, revealing the wisdom of a “professional” patient, Tiffany Christensen. Through journal entries, letters and essays, she provides a perspective of someone familiar with the medical system based on a lifetime of cystic fibrosis (CF) who has undergone two miraculous, life-saving, double-lung transplants. Tiffany shares her experiences, lessons learned and insights through clear, articulate and easy-to-read pages.

Tiffany’s approach was to create a “user’s manual” for patients on how to navigate the medical system, and how to cope with illness and poor prognosis. It is a valuable educational tool for medical personnel, patients, as well as families and partners of people with any chronic, life-threatening illness. She weaves into the instruction manual short vignettes about her life and the valuable lessons learned. Her writing is personal, honest and endearing and leaves the reader feeling like one knows the author intimately. Each chapter left me reflective, grateful and empowered.

Tiffany touches on many areas such as: the value of reaching out to a support

system, body image, acceptance, faith, communication with medical personnel and insurance companies, maintaining a positive attitude and keeping a sense of humor. She teaches readers to empathize. It was easy to imagine myself in that place of helplessness as the body gives out. Yet, her teachings also shine with hope, showing how the will to live can surpass even the grimmest prognosis.



This is not a depressing book. Tiffany’s sense of humor comes through even in the

most frustrating moments, and I found each chapter entertaining as I laughed and cried along with her. Tiffany gave a gift to society in this one-of-a-kind book. I feel privileged and inspired to recommend:

[www.sickgirlspeaks.com](http://www.sickgirlspeaks.com).

*Ed Note: Tiffany Christensen will speak at our Educational Conference in August at the Sofitel San Francisco Bay (see page 5).*

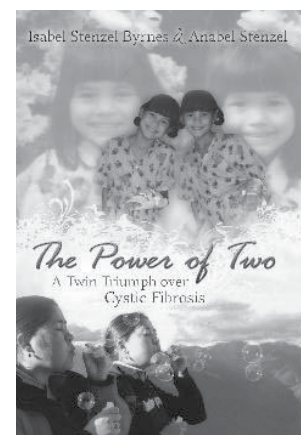


## The Power of Two

Reviewed by Beth Sufian

If you read one book this year, make it *The Power of Two*. The book is easily the most compelling book in what has now become a crowded field. In addition, I can say without hesitation it is simply one of the best books I have ever read. Anabel Stenzel and Isabel Stenzel Byrnes are household names in the CF community. The book tells about their childhood, teenage years and their path to lung transplantation. While reading the book I realized I knew nothing about their lives before 1996. The book is easy to read and honest, even about subjects that many with CF would rather keep private. By writing about both their struggles and triumphs, Anabel and Isabel impart their wisdom for accepting both the good and bad that come with a life challenged by chronic illness.

It’s a must read for anyone with CF, anyone who loves someone with CF or works with people with CF. Even pharmaceutical representatives have told me the book has given them a much needed education. The story will touch the hearts of readers and show them how these two remarkable sisters faced adversity with extraordinary determination and courage. At a time when our popular culture holds up movie stars as heroes, Anabel and Isabel show us the makings of true heroes in our midst.





**Cystic Fibrosis Research, Inc.  
21<sup>st</sup> Annual Education Conference**

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

**August 1-3, 2008  
Sofitel San Francisco Bay  
A Four-Star Hotel  
Redwood City, California**

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



**Presentations include:**

***“Improving Lung Function By Controlling Infection”***

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

***“Cystic Fibrosis Related Diabetes”***

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

***“Strategies to Reduce Time For Airway Clearance”***

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

***“Complementary and Alternative Medicine”***

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

***“CFRI Research: The New Horizons Campaign”***

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

***“CFRI Research: The Elizabeth Nash Memorial Fellowship”***

Jonathan Widdicombe, PhD, University of California Davis, CA

***“Sexuality and Reproduction in Cystic Fibrosis”***

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

***“Compliance”***

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

***“Sick Girl Speaks!”***

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

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

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

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

*Scholarships are available but limited to eligible applicants.*

## Visit a New CF Resource: [www.CFLiving.com](http://www.CFLiving.com)

CFRI is excited to share a new program called *CF Living*, a free online resource offering educational information, tips on leading a healthy lifestyle and support for patients and caregivers.

By encouraging patients and caregivers to take a more active role in the management of the disease, *CF Living* assists them in getting more out of appointments through identifying important questions to ask healthcare professionals.

The *CF Living* web site includes:

- A *Personalized Care Team Discussion Guide* with tips for how to engage in an open dialogue with your CF Care Team;
- A series of educational e-mails to help you learn more about CF and tips to better manage it;
- Access to online resources for continued learning.

To enroll in *CF Living* or learn more, visit [www.CFLiving.com](http://www.CFLiving.com).

This program was created by **Genentech, Inc.** as part of the company's continued commitment to provide information and resources to individuals with cystic fibrosis and their caregivers.



## Who Inspires You?

We're inspired by the amazing and remarkable achievements and attitudes displayed by so many individuals in our community. For nearly four years, Genentech's *Heroes of Hope Living with CF* program has recognized those who exemplify heroism. Past heroes raised money toward CF research, provided thousands with free CF legal advice and volunteered. These award recipients are united by their common traits of maintaining a positive attitude, proactively maintaining their health and making the most of their lives.



Molly Pam, a hero of hope.

site, [www.heroesofhope.gene.com](http://www.heroesofhope.gene.com), to download a nomination form, and fax or mail in. An independent Advisory Panel comprised of 7 members of the CF community selects recipients.

This year, the program is moving online to give everyone access to these inspirational stories.

Once selected, a *Heroes of Hope* recipient will:

- be able to record a downloadable podcast;
- Receive a personalized page on the web site featuring their podcast, a collection of photos and their biography;
- Be honored with an award, a certificate and t-shirt.

*Heroes of Hope* has recognized almost 40 outstanding individuals with CF across 30+ states. Anyone can nominate a person with CF to be a *Hero of Hope* – just log onto the newly-renovated web

Who is your Hero? To nominate one (or several) and learn about past recipients, log on today: [www.heroesofhope.gene.com](http://www.heroesofhope.gene.com).



## Special Thanks to Los Altos Sunset Rotary!



The Golden State Road Warriors Basketball Team assisted in raising over \$3,250 for CFRI programs late last year. Pictured with the team are Carroll Jenkins, Executive Director of CFRI, and young Mackinnon Baugh who played that night. The fundraiser was organized by the Los Altos Sunset Rotary Club.

# CFRI Founding Member Maxine Eggerth

by Ann Robinson

CFRI founding member Maxine Eggerth has been actively fundraising for cystic fibrosis since 1954 when her oldest son John was diagnosed with CF at age seven.

## OUR FOUNDERS

### Where are they now?

In 1975, a handful of dedicated volunteers created CFRI. The mission then was close to our mission today: fund research to find a cure; and educate, advocate and assist those who suffer from this disease. Former Executive Director Ann Robinson and long-time member Francine Bion are working together to bring us an update on our founders.

Based on our records and updated from our interview with Maxine, here is the list:

Maxine Eggerth  
 Ann and George Graham  
 Don and Merrilyn Holmes  
 Elizabeth (Betty) Meyer  
 Chuck and Jodi Nelson  
 Frank and Pat\* Thibault  
 Heath and Gail Wakelee  
 Art and Mary Lou Wigg  
 Joy\* and Chuck\* Witt  
 Bob, Sr. and Bernie\* Stewart  
 Jackie Stewart  
 Al and Elaine Peterson  
 Marge\* and Shell Trask  
 John and Cathy Gaspari.

*\*Some of those pioneers have since passed on.*

If you have any information on these founders or other early contributors, please e-mail [DBatchelder@CFRI.org](mailto:DBatchelder@CFRI.org) or phone him at 650-404-9978.

She was living in New Jersey so John was treated at Presbyterian Hospital in New York City. John's treatment consisted of sleeping in a mist tent every night and taking antibiotics when he was sick. Maxine's younger son Rick does not have CF.

Maxine learned about CF mostly from John's doctors and from the few brochures published – there was not a lot of information on CF in the early years. When Maxine and her family moved to California, John was first seen by Dr. Mitchell in Oakland. Then he transferred to Dr. Birt Harvey's practice at Children's Hospital at Stanford. As John's illness progressed during his adolescence, he was hospitalized more frequently. Just prior to John's death at age 21, a physician friend of Dr. Harvey's commented that John's x-rays looked like that of a 90 year-old man.

In California, Maxine was active in the CF community and as other families worked to raise money for research, they became close friends, offering support

to each other. In 1975 this group decided to form their own nonprofit organization because they wanted to control how their funds were spent.

When CFRI (Cystic Fibrosis Research, Inc.) was incorporated as a 501 (c) (3) nonprofit in November 1975, Maxine was active and held many board offices. She was also Chairperson for the Mothers' Day Tea. In 1976 the group was excited when their first Mothers' Day Tea brought in \$750. Maxine has been a CFRI tea sender for 32 years and looks forward to sending tea invitations again this year! She also continues to volunteer in the CFRI office.

Maxine, 89, has three grandchildren. She is proud CFRI has grown into such a large organization educating many people about CF. She is also excited about CFRI's funding medical research that is extending the lives of CF patients while enabling those with cystic fibrosis to live longer, more productive lives.

Thank you Maxine for being a CF volunteer for 54 years!



## CF Affects the Liver Too –

(Continued from page one)

cal processes controlled by estrogens. Estrogens are important because they regulate the levels of many proteins and enzymes in the liver. Our laboratory initially observed that in mouse models of CF an important drug and estrogen metabolizing enzyme, sulfotransferase (SULT) 1E1, was greatly increased in the livers of the CF mice. The SULT enzymes attach a large charged sulfonate group to drugs and hormones thereby inhibiting their activity. Therefore, SULT1E1 is important in regulating the activity of  $\beta$ -estradiol, the major estrogen in humans as well as mice, at the concentrations normally found in tissues. The large increases in SULT1E1 result in a decrease in the activity of estrogens in the liver and changes in the levels of many enzymes and proteins normally regulated by estrogens.

### Lower Body Weights

In CF mouse models the animals tend to have lower body weights than healthy mice. This is mostly the case with

children who have CF too and these findings led us to investigating the role of  $\beta$ -estradiol in the regulation of the synthesis of IGF-1 in hepatocytes. IGF-1 is an important hormone in regulating bone and tissue growth in children. Over half of the IGF-1 in the circulation is made and released by the liver.  $\beta$ -Estradiol in hepatocytes helps cause an increase in SULT1E1 in hepatocytes. Cholangiocytes are the cells that form bile ducts in the liver. The hepatocytes are the main cell type in the liver and make up about 90% of the cell content in the liver. CFTR is present in cholangiocytes but not hepatocytes. SULT1E1 is present in hepatocytes but not cholangiocytes. A model system is being used in which human cholangiocytes are grown in the same dish as human hepatocytes but separated by a porous membrane that allows factors released by the cells to pass through to the other cell type. When CFTR synthesis is selectively inhibited in cholangiocytes as occurs in CF, these cells are capable of causing an increase in SULT1E1 levels in the hepatocytes indicating that during CF cholangiocytes

are releasing factors that can alter the biochemistry of the hepatocytes.

***This knowledge can then be used to design therapies to prevent or treat these developing changes.***

Since the lifespan of individuals with CF is increasing, the effects of CF in tissues, such as liver, need to be better understood so that treatments can become more focused and effective. Changes in the biochemistry of hepatocytes including increased SULT1E1 activity may have slow-developing long-term effects on liver function including inflammation and liver damage. Altering the activity of important hormones like  $\beta$ -estradiol will have many subtle effects on the function of tissues and organs that remain to be understood. This knowledge can then be used to design therapies to prevent or treat these developing changes.

## Stanford CF Education Day March 15th

Stanford hosted its eighth annual CF Education Day this past month at Lucile Packard Children's Hospital in Palo Alto, CA. Outstanding presentations included Drugs in the Therapeutics Pipeline, CF Newborn Screening, Infection Control Guidelines, Pulmonary Exacerbations, the Role of Salt in the CF Diet, an update on Respiratory Diagnosis and Treatments, and short research presentations.

In addition, an exciting new program was introduced which addresses the health of the whole person with CF through Transpersonal Psychology.

Fourteen speakers covered a wide range of issues during the six-hour

education day attended by about 75 participants, including doctors, nurses and other hospital employees, researchers, etc., along with CF caregivers and those suffering from the disease. Dr. Richard Moss, Director of the CF Center, presented some findings too and served as moderator.

To find out more, check our website ([www.cfri.org](http://www.cfri.org)) for a listing of this event's presentation captured on video and available on DVD's.



Pictured here from left to right are:

Phillip Weichel,  
Director of Field Management, CFF;

Carroll Jenkins,  
Executive Director, CFRI;

Chris Ruetz,  
Executive Director, CFF, No. CA Chapter.

# GHPP Offers Medical Resources to California Residents with CF

By Darlene Batchelder

**H**ere in the State of California we are fortunate to have a state agency that acts as a comprehensive medical payer of last resort for people with cystic fibrosis and other genetic illnesses. GHPP or Genetically Handicapped Persons Program is a unique program that falls under the State Department of Health Care Services and may cover anyone over 21 and anyone under 21 who has been denied services by CCS, California Children's Services.

If you have CF, whether you work or not, and whether you have health insurance or not, you can enroll in GHPP and simply pay an annual enrollment fee (one must re-enroll in the program and prove eligibility annually). If you have insurance or are covered by Medicare, Medical or a private HMO or PPO, you may still receive benefits under the program.

## *There is no income limit for GHPP eligibility*

You must submit an 8 page application with personal, medical and financial information. You must also provide proof of California residency with a driver's license, voter registration or utility bill statement. GHPP will review your application and inform you of the annual enrollment fee. For an individual with an income of \$21,000 or less the annual fee is about \$60.00, and the fee increases in increments of \$60.00 based on income and family size. There is NO income limit for eligibility.

Why bother to enroll if you currently have health insurance? The program mission is "to provide coordinated medical care through case management services that assures partnerships among the Special Care Centers, SCC team and the client's community health providers." Their intention is to provide the most comprehensive services available at a CF Center. GHPP's program goals are early identification and enrollment of people with genetic illnesses, high quality, coordinated, ongoing care

by qualified medical doctors and care providers, providing preventative and ongoing treatment services. So, the coordinated and comprehensive care you receive complements and enhances services provided by your existing insurance.

Furthermore, GHPP provides protection for people with CF in case they lose their employment or insurance. It also allows them to work part time or be self employed and continue to receive benefits as if they were insured.

## *What does GHPP cover?*

There are currently about 445 people with CF enrolled in GHPP in California. The services they receive include but are not limited to: typical CF medications like Tobi, Pulmozyme and enzymes, hospital stays, outpatient medical services, surgeries, nutrition products and medical food, lab work, x-rays and other tests, durable medical equipment, home infusions and enteral nutrition, lung transplants, critical care. Also, since GHPP is a comprehensive program, CF-related illnesses, like diabetes, even vision and dental needs are covered.

For more information on GHPP, go to their website at [www.chcs.ca.gov/services/ghpp](http://www.chcs.ca.gov/services/ghpp). Check out the sections on eligibility, benefits, questions and the application which you will find in the "INDIVIDUAL" section. You may contact GHPP, Monday through Friday, from 8 am to 5pm at: (916) 327-0470 or (800) 639-0597.

## *What About Other States?*

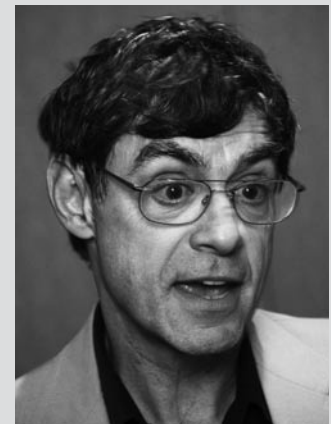
Other states (thirty one as of February 2008) offer SPAPs (State Pharmacy Assistant Programs) to the disabled, low income seniors and the uninsured. Another 7 states have recently passed laws or issued executive orders to create such programs. To find out if your state offers an SPAP or drug discount program, check out the national conference of state legislature's site: [www.ncsl.org/programs/health/drugaid.htm](http://www.ncsl.org/programs/health/drugaid.htm)

## CFRI Semi-Annual Membership Meeting

*Mark Your Calendars,  
May 28, 2008 – Palo Alto, CA  
"Special Needs Trusts"*

Twice a year CFRI hosts a meeting for its members to get their input and report on progress. This May meeting will include a presentation on Special Needs Trusts, the subject of our lead article in *CFRI News*. Michael Gilfix is an experienced attorney who specializes in this area and will present, and then answer any and all questions. (Michael spoke at our educational conference last August.)

Our business meeting begins promptly at 7pm, with Michael's presentation beginning at 8pm. Our meeting will again be held at Lucile Packard Children's Hospital Auditorium in Palo Alto, CA. Call our office if you have questions or need directions (650) 404-9975. Parking is available for a nominal fee.



Michael Gilfix, Esq. at our 2007 Annual Conference

# Newborn Screening for Cystic Fibrosis in California – A Vignette about Elsa

Ruth Koepke, M.P.H., Research Scientist and Martin Kharrazi, Ph.D., Chief Program Research and Demonstration Section, Genetic Disease Screening Program, California Department of Public Health.

**E**lsa was born at Kern Medical Center in Bakersfield, CA, on Monday, July 23, 2007. After a day of feeding, sleeping and bringing great joy to her first-time parents, Elsa, like the other 11,150 babies born in California that week, had her Newborn Screening Test. First, her heel was gently pricked and a few drops of blood were collected onto a special filter paper card. After the blood spots dried, the collection form and card were put into an envelope with specimens collected from other newborns tested that same day. Together the collection forms and dried blood spots were sent to the California regional Neonatal and Prenatal Screening (NAPS) laboratory located at Fresno Community Hospital.

On Wednesday, after having her first bowel movement, Elsa was discharged from the hospital with her parents. At home, Elsa fed vigorously and appeared healthy, but

often had runny bowel movements. Elsa's pediatrician told her parents that runny stools were normal for breast-fed infants.

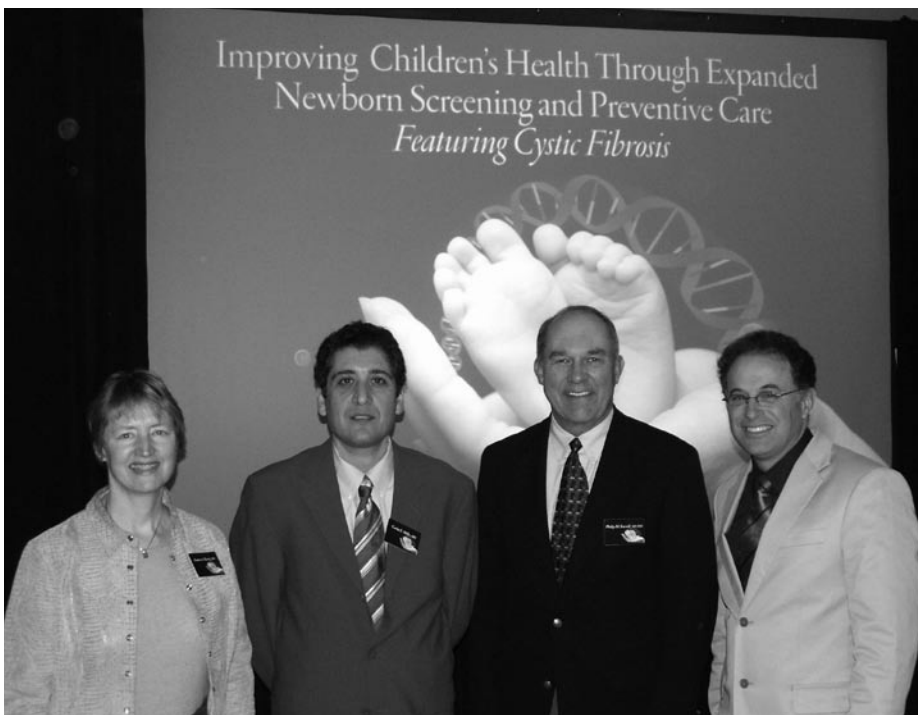
On Thursday, the blood spots arrived at the regional NAPS lab in Fresno. There Elsa's blood spot joined the specimens arriving from all the other hospitals in the region. All newborns' blood spots were screened for the 28 disorders recommended by the American College of Medical Genetics and March of Dimes Birth Defects Foundation as well as 47 additional disorders. The disorders include multiple metabolic conditions such as phenylketonuria (PKU) and galactosemia; sickle cell disease; primary congenital hypothyroidism; congenital adrenal hyperplasia and cystic fibrosis (CF). Elsa's blood spot was found to have one abnormal finding - an elevated level of a protein called immunoreactive trypsinogen (IRT), which is usually elevated in infants with CF. Because of its elevated IRT level, Elsa's blood spot

was sent to Stanford University's Molecular Pathology Laboratory for further testing. Elsa's blood spot was one of 178 newborn blood spots with elevated IRT levels sent to the Stanford laboratory that week from the seven NAPS laboratories across the state.

Elsa's blood spot arrived at the Stanford laboratory the following week. A portion of Elsa's blood spot was placed in a test tube so that a segment of her DNA could be analyzed. This segment, the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) gene, carries at least one mutation in each chromosome in persons with CF. The test conducted at Stanford identifies the presence of one or more of 38 different CF disease-causing mutations common among Californians. The DNA analysis of Elsa's blood spot identified one copy of the common mutation "delta F508". Because only one CFTR mutation was identified, a portion of Elsa's blood spot was routed to Ambry Genetics to search for the presence of a second CFTR mutation. That week, Elsa was one of 11 infants in California whose blood spots were routed to Ambry Genetics.

At Elsa's two week check up, the pediatrician noticed that Elsa had not gained very much weight since birth. The pediatrician suggested that Elsa's mother supplement her breast feeding with formula.

Two and a half weeks after her birth, Elsa's pediatrician and birth hospital each received a letter from the California Department of Public Health Newborn Screening Program (NBSP) indicating that one CFTR mutation had been identified and that further mutation testing was being conducted on Elsa's blood spot. That week, Elsa's blood spot arrived at Ambry Genetics. During the blood spot's three week stay at the laboratory, a portion of the blood spot was used to analyze the CFTR gene in detail using a process called focused DNA sequencing. Unlike the test at Stanford, the test conducted at Ambry can identify nearly all significant mutations in the CFTR gene. Ambry confirmed



Philip M. Farrell, M.D., Ph.D. (third from left) presented "Improving Children's Health Through Expanded Newborn Screening and Preventive Care, Featuring Cystic Fibrosis" to a group of doctors, nurses and CF professionals in Palo Alto on February 9th. Others participating on the Q & A panel included, from left, Karen A. Hardy, M.D.; Carlos E. Milla, M.D.; and Marty Kharrazi, Ph.D.

the presence of the delta F508 mutation and also identified the presence of another known, disease-causing CFTR mutation called "S945L".

At four weeks of age, Elsa's mother took her to see the pediatrician because she was having a croupy cough. The pediatrician checked Elsa's lungs and ears, prescribed antibiotics and sent her home. Elsa's weight was still not as high as it should have been.

On Wednesday, five and a half weeks after Elsa's birth, Ambry Genetics alerted the NBSP of Elsa's two CFTR mutations. That day, the NBSP Area Service Center (ASC) follow up coordinator at Children's Hospital Central California (CHCC) called Elsa's pediatrician to notify him of Elsa's positive newborn screening result for CF. The pediatrician notified Elsa's parents of the screening results and referred them to the CF Specialty Care Center at CHCC. The ASC staff assisted the pediatrician and Elsa's parents with scheduling the appointment for Elsa. The CF Care Center Coordinator telephoned Elsa's parents to answer their questions and to instruct them on how to prepare Elsa for the diagnostic sweat test.

One week later, Elsa was evaluated by the CF Care Center. Elsa's sweat test was positive for CF. The CF Care Center noted that Elsa had abnormal stools, signs of malabsorption and was underweight, but overall was in good health. The CF

Care Center started Elsa on pancreatic enzymes, vitamins and lung percussion therapy. Elsa's parents were given CF educational materials prepared by the NBSP, CFRI and the Cystic Fibrosis Foundation (CFF).

Because of newborn screening, Elsa obtained a diagnosis of CF early in life,

## CF Newborn Screening by State

Thirty-five states currently have implemented mandatory CF newborn screening and an additional six states are soon to come on board, according to the March of Dimes web site. Since Newborn Screening is legislated on a state-by-state basis, check your health department if you have further questions.

As of early 2008, Alabama, Illinois, Maine, Nevada, North Carolina, Utah and Vermont have not yet implemented mandatory CF Newborn Screening. Connecticut and Pennsylvania offer CF testing by request.

before irreparable damage could occur in many organ systems. She avoided a potentially long and arduous diagnostic odyssey. However, early diagnosis is just the first step in the care that will be needed to maintain Elsa's health and that of the expected 85 other infants with CF that will be identified by the NBSP each year in California.

*\* Elsa is a fictitious name. Her experiences described in this article are also fictitious and are being used for illustrative purposes only.*

## Why is Newborn Screening Important?

By Darrell Batchelder

Mandatory CF testing has gone from a handful of states in 2003 to over 40 states today. Why have so many states passed this legislation?

Seventy-eight percent of California Newborns with CF show no outward signs of disease at birth. It often takes months, sometimes years to discover CF and in the meantime the disease has a head start. Many states have concluded that to begin treatment early will prevent or delay some expensive hospitalization. Our son Joe was born in 1988 at six pounds, eleven ounces. (A first year of growth is critical and most children gain three times their body weight in their first year.) Eleven months later, when Joe's failure to thrive was finally diagnosed as CF at Stanford Children's Hospital, he'd gained only four pounds.

Newborn Screening makes all the difference regarding how big and strong a child may grow during the time the disease goes undetected. Joe at twenty years old today is 5'4" and weighs 130 lbs. His brother who does not have CF is 5'10" and weighs 165 lbs.

When CF infants are identified within the first sixty days and treatment begins early, it generally means better growth, increased weight, less lung problems early, and a better chance to fight the disease. Early detection and prompt treatment may make a big difference in potentially extending life expectancy.

### CF Newborn Screening Program Summary

(as of February 28, 2008)

	<b>Number</b>
Date program started	16-Jul-07
Total newborns screened	358,297
Newborns with positive screening results for CF	117
CF cases confirmed — Total	24
2 CFTR mutations identified by Stanford's laboratory	15
1 CFTR mutation identified by Stanford's laboratory and	
1 CFTR mutation or more identified by Ambry Genetics	9
Hispanic	11
White	11
Hispanic Black	1
Hispanic Hawaiian	1
Older siblings of infants with positive CF NBS results diagnosed with CF	3
CF carriers detected	179
Newborns with positive CF NBS results pending final diagnosis	79
CF birth prevalence — expected	1 in 6,033
CF birth prevalence — minimum estimate based on CF NBS results	1 in 11,581

# Your CFRI Research Dollars at Work in 2006-2008

Your donations make possible our continuing efforts to research a cure and fund the projects listed below. Over the past 33 years your generous contributions have funded many important projects that led to a better understanding of this disease.

These are the scientists, medical professionals and researchers, and their studies, leading to our ultimate goal of a cure for CF. A story on Dr. Charles Falany's work, begins on page one. A meeting of researchers in CFRI's Elizabeth Nash Memorial Fellowship and their sponsors is summarized briefly below.

## 2007-2008 Elizabeth Nash Memorial Fellowship

**Joanne Engel, M.D.**  
**Keith Mostov, M.D.**  
University of California,  
San Francisco Lab  
"Lung Mucosal  
Glycosylation  
and *Pseudomonas*  
Binding"

7/1/2007-6/30/2008

**Iwona Bucior, Ph.D.**

**Jeff Wine, Ph.D.**  
**Daya Upadhyay, M.D.**  
Stanford Lab  
"Clinical and Basic  
Research Studies of  
CF Gland Secretions"

7/1/2007-6/30/2008

**Monal Sonecha, M.D.**

**Jason Eiserich, Ph.D.**  
**Carroll Cross, M.D.**  
University of California,  
Davis Lab  
"Oxidative Stress  
in CF Respiratory  
Tract Secretions:  
Therapeutic Strategies"

8/1/2007-7/31/2008

**Vihās Vasu, Ph.D.**

**Paul Quinton, Ph.D.**  
University of California,  
San Diego Lab  
"Does Poor Bicarbonate  
Secretion Impair Cervical  
Mucus Release in CF?"

7/1/2007-6/30/2008

**Ruth Mucchekehu, Ph.D.**

## 2006-2008 New Horizons Research Campaign

10/1/06 – 9/30/08

**Jonathan Widdicombe, Ph.D.**  
University of California Davis  
"CFTR vs. Ca-activated Chloride  
Channels in Airway Glands"

10/1/06 – 9/30/08

**Charles Falany, Ph.D.**  
University of Birmingham, Alabama  
"Estrogen Sulfation in the Dysregulation of Hepatocyte Growth Hormone Signaling in Cystic Fibrosis"

10/1/06 – 9/30/08

**Isabel Virella-Lowell, M.D.**  
Medical University of South Carolina  
"Loss of Acid Sphingomyelinase of Hepatocyte Growth Hormone Signaling Induction by *Pseudomonas aeruginosa* in Cystic Fibrosis"

## 2006 Other Grants

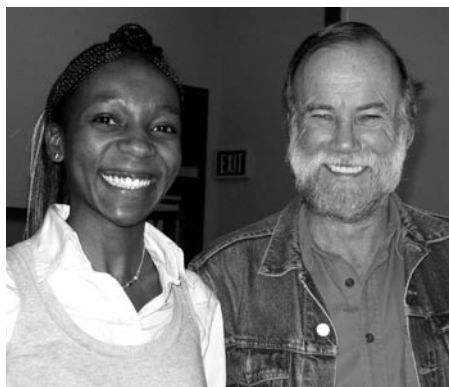
November 1, 2006

**Terry Machen, Ph.D.**  
University of California Berkeley

"Flagellin-Stimulated Secretion and Inflammation in Airway Epithelium"



## Post-Doc Fellowship Colloquium



Ruth Mucchekehu, Ph.D. and her sponsor, Paul Quinton, Ph.D. pictured here were two of the meeting participants.

Twice a year the participants in the Elizabeth Nash Memorial Fellowship meet to share their findings with each other and their sponsors (see names above). All were in attendance and were able to ask questions on progress, methodology and share their ideas allowing for an interaction that furthers their individual research. In addition, two CF researchers outside of our program added to the four-hour seminar discussion and provided comments and ideas from their unique perspectives.

## SNT Special Needs Trust *(Continued from page one)*

drafted SNT establishes a management team, sets up a system for the beneficiary's lifelong advocacy and care, plans for future modifications in public benefits and trust law, and directs distribution of remaining assets after the death of the disabled beneficiary. Even a well crafted SNT will not work if trustees do not understand all that is required. This is why selection of a management team/trustees is typically the most important decision to be made.

An SNT that is funded with assets and is being used for a disabled beneficiary must be irrevocable. It is, however, possible to have a revocable third party SNT. A common practice among attorneys experienced in this area is to establish a stand-alone revocable SNT, alongside the settler's revocable living trust.

Tying up money in a trust means planning for "what if"? If the parents pass away, who will be the trustee? Should a family member be the trustee? Where would you want money to go if your beneficiary passes away? This is all part of the contingency plan. You may choose supplemental beneficiaries if your primary beneficiary passes away.

Administration of both SSI and Medi-Cal are also subject to agency administrative guidelines which can change frequently. The Social Security Administration's is available: <http://policy.ssa.gov/poms.nsf>. – and Medi-Cal is governed by guidelines shown here: <http://www.cms.hhs.gov/manuals>. Unlike SSI and Medi-Cal, Social Security Disability Insurance and Medicare have no income or resource requirements. Many persons with a disability and their families confuse Social Security disabled child benefits with SSI benefits because the cash payments are almost the same and both checks come from the Social Security Administration.

## Another View

There are others who believe SNTs are not always the best choice for families affected by CF. SNT legislation was enacted mainly due to the efforts of the Developmentally Disabled community. These people who probably never worked and were on SSI and Medicaid

lost benefits when their parents died and they inherited money. These disabled people typically have different situations than people with CF. SNT may work better here because they typically use Medicaid as a safety net and do not have the high monthly drug and treatment costs associated with CF. Most of these people have little chance of recovery, unlike people with CF who may be sick and then return to work.

A major consideration is whether your young adult is working. If they have worked full or part time and contributed to Social Security, then they may qualify for SSDI, which is not financial based to qualify for benefits. Also in California the Genetically Handicapped Peoples Program is available for all with CF and is not based on financial need. However, if your child or young adult has not worked due to disability and you don't believe they will in the future, then you might look closely at an SNT. This is the only way to protect assets and keep SSI and Medicaid benefits at the same time since they require you to have less than \$2,000 in assets.

A typical SNT covers basics such as food, clothing and medical assistance not covered by governmental assistance programs. Tying up an inheritance in a trust that is too restrictive could backfire. We've heard of instances where literally millions of dollars were left in an SNT and it was difficult if not impossible for the trustee to distribute money except for restrictive, limited items outlined within the SNT. Finally, there is also a "pay back" requirement for Medicaid if the agency decides that money in an SNT was improperly distributed. In other words, a trust improperly crafted and a trustee not aware of the pitfalls may cause more harm than good. A decision made by a bureaucratic agency might cost a lot if the pay back provision is implemented.

You should educate yourself on your particular situation as well as educate your Special Needs Attorney on CF when planning your estate if you choose to establish a SNT. Your selection of a trustee needs to include their knowledge on what governmental agencies will consider proper (or improper) distributions. For this reason, particularly in a larger legacy, you

might consider three trustees; one in the traditional role, another financial investment professional to grow the trust securely, and an attorney who periodically reviews the trust in terms of any changes in the law. The SNT should be crafted in such a way that allows some flexibility and room for changes in governmental policies over time – as much as possible.

## Memorandum of Intent

The parents of a disabled child are often his or her greatest advocates. When the parents die their child's care may suffer. For this reason a Memorandum of Intent outlining your wishes for the child and their care will give trustees a direction for future decisions. This is part of responsible estate planning.

No two families or situations are alike. Your choices will be determined by whether your child can work and will qualify for SSDI or will need SSI only as well as many other factors. It is very important to be fully informed when making these decisions.

If you have questions regarding SNTs, join us at our General Membership Meeting when Michael Gilfix will be the featured speaker on this topic. The meeting will be held May 28<sup>th</sup> at 7pm (Michael to speak at 8pm.) in the Lucile Packard Hospital Auditorium in Palo Alto, CA.

*CFRI is not prepared or qualified to answer questions or recommend a course of action. What we did was ask legal experts about the challenges and pitfalls in SNTs. Consider appropriate legal counsel to discuss your situation. No two families are identical. Choosing a trustee and creating an ongoing contingency plan is always unique.*

Contact information for the two California SNT attorneys consulted:

Kevin Urbatsch, Esq., 415-710-7886  
[www.UrbLaw.com](http://www.UrbLaw.com)

Michael Gilfix, Esq., 650-493-8070  
[www.Gilfix.com](http://www.Gilfix.com)

You may also "Google":  
"CF Information Hotline" (sponsored by Novartis on the CFF website).

## 24<sup>th</sup> Annual CFRI Golf Tournament

**Monday, August 4<sup>th</sup>, 2008  
Cinnabar Hills Golf Club  
23600 McKean Road  
San Jose, CA 95141**

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

For more information:  
Scott Hoyt at 408-323-7803 or  
[SHoyt@CinnabarHills.com](mailto:SHoyt@CinnabarHills.com)



## Drug Trial Breakthroughs Require More Volunteers

The North American CF Conference held in Southern California last October, attracted over 3,000 researchers, doctors and other CF professionals. The conference gives researchers the opportunity to share ideas and collaborate with others in the field of cystic fibrosis.

Dr. Felix Ratjen, a respected physician and scientist said at the conference, "In 2003, only 500 volunteers were needed for drug trials." He estimates 6,000 volunteers will be needed for 2009. If you have CF, or are a caretaker, ask your CF Center doctor about participating in future trials. The sooner drugs get through the trial testing process, the quicker they can assist in better managing various aspects of CF.

*(Information provided by USACFA's CF Roundtable, Winter 2008 edition and printed with permission.)*

# Rocking The House: Sixty-Five Roses Concert

By Siri Vaeth-Dunn

As Tess Dunn, a 13-year-old with cystic fibrosis, sat at the keyboard facing over 200 adoring friends, family and new fans, she admitted, "A minute ago I was hanging out backstage with Nina, and I said, 'Whoa, I'm nervous!'" Tess went on to confidently perform three of her original songs, with the powerhouse singer/songwriter Nina Storey providing back-up harmonies.

As expected, Tess and Nina brought down the house.

This was all part of the "Sixty-Five Roses" concert, held February 16<sup>th</sup> at Moe's Alley Blues Club in Santa Cruz, California. The brainchild of Bill Welch— owner of Moe's Alley and Tess' friend and neighbor – the event raised CF awareness, as well as over \$6,000 for CFRI. "Sixty-Five Roses" refers to the common childhood mispronunciation of cystic fibrosis, and roses were in abundance on stage and throughout the club. In addition

to Nina and Tess, Amanda West, Adrienne Pierce, and Ari Shine shared their phenomenal talents during the afternoon concert.

Between musical acts there was special recognition of the siblings of those living with cystic fibrosis, including Anni Barnes, whose sister Lucy has CF, and Tess' brother Dylan. The two played a key role in selling over \$1,500 worth of raffle tickets.

This was the third CFRI benefit by Nina Storey. In the six years since they first met, Nina has become a mentor to Tess, and the respect is mutual. In an interview with the local newspaper, Nina said about Tess, "She's been a role model to me... to see how she's grown and prospered is very gratifying."

*To find out more about the musicians that shared their talents, visit their websites:*

[ninastorey.com](http://ninastorey.com); [arishine.com](http://arishine.com);  
[adriennepierce.com](http://adriennepierce.com);  
[amandawestmusic.com](http://amandawestmusic.com)



Tess Dunn sings and plays one of her songs. Tess is 13, has CF, and has been playing piano for eight years. Tess says, "I try to write one song a day." Harmonizing with her is Nina Storey, one of four professional musicians who helped to raise more than \$6,000 for CFRI in February. CFRI wishes to thank the owner of Moe's Alley Blues Club, Bill Welch, for his generous support of this fundraiser.

# Mothers' Day Tea Kick-Off



From left to right, Gerald Brady, Pat Flynn, Francine Bion and Ann Robinson were a few of the attendees at CFRI's Mothers' Day Tea Kick-Off in March.

Tea Senders gathered at the Palo Alto home of Dr. Jeff and Marlene Wine in early March to celebrate CFRI's Mothers' Day Tea kick-off.

Close to 300 tea senders annually send an invitation to people they know asking them to share a cup of Bigelow tea. This year the flavor is "Perfect Peach". And as their friends are enjoying a brief respite with their cup of tea, they consider a donation to support CFRI's mission.

It is not too late to receive (or to sign up as a tea sender) or send out invitations to your friends. For additional information, please call our office at 650-404-9975 or send an e-mail to: [CFRI@CFRI.org](mailto:CFRI@CFRI.org). We'll be delighted to provide you with everything you need to be a tea sender.



Julie Judge won our Mothers' Day Tea raffle and this lovely Spode teapot donated by Pat Flynn. Julie's name was drawn from a list of everyone who signed up for our Mothers' Day Tea program by March 17th.

## 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

[Clip out and send to CFRI 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043.  
Or give us a call at 650-404-9975 to place an order.]

# ANNOUNCING THE CYSTIC FIBROSIS TEEN & ADULT DAY RETREAT

August 3 – August 8, 2008

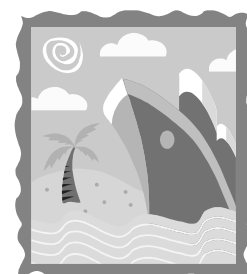
Located at Vallombrosa Center in Menlo Park, California

This Year's Theme:

## CF Club Med: Retreat of a Lifetime!



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



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

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

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

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

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

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

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### We'd Love To See You There!

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

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

Phone: (650) 404-9975 [cfri@cfri.org](mailto:cfri@cfri.org) Fax: (650) 404-9981 [www.cfri.org](http://www.cfri.org)

### An Invitation to the CFRI Teen and Adult Day Retreat

By Anna Modlin

A summer week full of fun, learning, and living is what you'll find at this year's CF teen and adult day retreat. The theme is CFRI Club Med: Retreat of a Lifetime!

Retreat is the place for you as we focus on support groups, exercise, fun, laughing, as well as educational activities. The planning committee extends an invitation to anyone in the CF community. While many are hesitant to socialize with fellow CFers due to cross infection concerns, we maintain strict guidelines and provide safety for individuals and families.

There is nothing that compares to sharing the experience of hospitals, doctor visits, medications, lung and digestive issues. This is a place to discuss what the outside world does not understand. For those who support a loved one, this is a place to gather more understanding of their CF experiences in a safe space to express your own hopes, fears and dreams.

We welcome newcomers with open arms (honoring the three-foot rule) and would love for our small retreat community to grow.

# Help Us Grow - Donate to CFRI

*Your Donations Support Vital CF Research and Education*

## 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](mailto:cfri@cfri.org).

## In Honor/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 special occasions.

## 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 650-404-9977.

## 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.

## 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. Both events create the opportunity to meet your philanthropic goals and provide positive tax benefits. Please contact us for information: 650-404-9975.

## CFRI Golf

At last 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! This 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](mailto:shoyt@cinnabarhills.com).

## Join Our Wine Club!

*"I had the opportunity to share with friends and it was delightful."*

M.B. - California

*"Bold-faced winner at a very affordable price. Thanks for the recommendation."*

A.P. - Baltimore

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

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

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

Questions?  
650-404-9978



**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.

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. Delivery is generally within three business days.

# In Honor of

(From September 1, 2007 to February 29, 2008)

The Casey Magner Family  
 The Christie Family  
 The Curry Family  
 The Friel Family  
 The Hardy Family  
 The Jones Family  
 The Lundy Family  
 The Mathews Family  
 The Robinson Family  
 The Stenzel Family  
 Sadie Anderson  
 Jessica Arvidson  
 Patrick Aspinall  
 Rebecca J. Atkins  
 Jamie Baker  
 Kyle Baker  
 Ian Baldwin  
 Bridget Barnes  
 Lucy Barnes  
 Joe Batchelder  
 Makinnon Baugh  
 Marin Baugh



***“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.**

Ann Robinson  
 Carl Robinson  
 Clare Robinson  
 Rob Robinson  
 Cortney Roeder  
 Elizabeth Rogers  
 Scott Sandler  
 Ben Sanford  
 Jean Sarkis  
 Peter Sarkis  
 B. J. Scherch  
 Shirley Schmeyer  
 Brady Scilingo  
 Margaret Kelli Selvage  
 Myranda Selvage  
 Janice Shaul  
 Rachel Silver  
 Joe Sinnavee  
 Matt Spadia  
 Ethan Spain  
 Megan Stacy  
 David Stadtner  
 Valerie Stage  
 Ben Staub  
 Casey Staub  
 Nick Staub  
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 Anabel Stenzel  
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 Briauna Red  
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 Rebecca Roanhaus  
 Ben Robertson

# In Memory of

(From September 1, 2007 to February 29, 2008)

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


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

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

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

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

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Ryan Coelho	Blake Kelley	Celia Newberger	Kevin James Swigelson
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Wiley Davis	Jeffery Kreth	Jennifer Ortman	Susan Thibault
Nadine De Alba	Jane Ellen Kulik	Dallas Pappas	John Thomson
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Gary Ray Adams  
Kimberly Adelman  
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Frank Baker  
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# 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**

Cystic Fibrosis Research, Inc.,  
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Federal ID# 51-0169988

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<b>Information</b>	(650) 404-9975	cfri@cfri.org

**www.CharityNavigator.org**, the web's  
guide to "Intelligent Giving" gave CFRI  
their highest rating. Only twenty-five per-  
cent of the charities rated were awarded  
four stars last year.

★★★★s



**CHARITY NAVIGATOR**  
Your Guide To Intelligent Giving

# 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.*

**CFRI** Cystic Fibrosis Research, Inc.  
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