

CFRI *news*

35 Years of Research, Education & Support

New!
CF
Discovery Series™

The Significance of Cystic Fibrosis Genotyping

By Siri Vaeth-Dunn

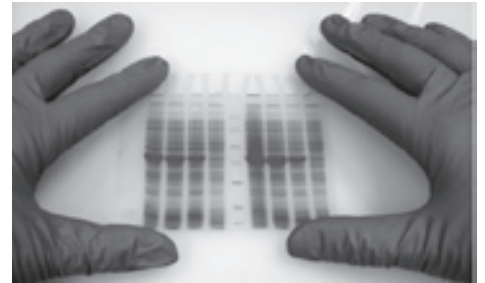
Cystic fibrosis (CF) is a capricious disease. Despite tremendous progress in its treatment, and an ever-increasing life expectancy, there is still a wide range of disease expression. While many adults with CF maintain active lives, children half their age still lose their battle with the disease. Numerous variables may impact CF's progression, including gender, access to health care, environmental impacts, socioeconomic status, pathogens in the lungs, and the development of cystic fibrosis related diabetes. Another factor is one's individual genetic mutation, which serves as an indicator of disease severity while playing an increasingly important role in the development of targeted treatments for specific genotypes.

Why is there such a broad spectrum of disease expression for those with CF? We know cystic fibrosis is caused by any one of a range of mutations in the cystic fibrosis transmembrane conductance regulator (CFTR) gene. When the CFTR gene was discovered in 1989, the Cystic Fibrosis Mutation Database was developed by an international alliance of 130 CF laboratories from 30 countries. Since its inception, the number of mutations in the database has grown exponentially with 1,717 listed as of April 2010. CFTR gene mutations have been grouped into five classes by researchers based on CFTR function. Two individuals with CF may have different mutations that contribute to a very diverse expression of the disease.

Dr. Carlos Milla, Director of the Stanford Cystic Fibrosis Center elaborates, "As the development of therapies aimed at correcting the CF basic defect evolves, it is increasingly apparent that some therapies work better than others depending on the type of defect the patient carries in the gene. Thus, it will be very important to

know what mutations the patient carries so therapeutic options available could be more clearly explored."

Studies show that CFTR mutations – and their associated class – can be correlated to pancreatic sufficiency. Other research has indicated that certain CFTR mutations are a predictor of increased risk of cystic fibrosis related diabetes. Dr. Milla says, "We currently know that the type of mutation determines the severity of the



CF protein dysfunction. The possibilities range from almost absolute absence of

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Healthcare Reform: Changes Affecting the CF Community

By Beth Sufian, J.D., Board Director,
U.S. Adult Cystic Fibrosis Association (USACFA)

After over a year of debate in Congress and around the country, **The Patient Protection and Affordable Care Act** became law on March 21, 2010. Often referred to as "Healthcare Reform," there are many parts of the new law that will help people with CF to obtain health insurance coverage. Sections of the law will be implemented in phases, with one section going into effect as early as June 2010, while others go into effect in September 2010, and others in 2014.

This article will discuss changes that will be implemented in June or September of 2010. Future articles will detail provisions of the law that take effect at later dates.



What will **The Patient Protection**

and Affordable Care Act provide citizens? The law does not create a national health insurance program, nor does it reduce the coverage that an insurance company can offer to policyholders. The law will make it easier for adults and children to obtain affordable insurance coverage. Healthcare reform removes current barriers that make it difficult for many with CF to obtain affordable coverage.

Below is a summary of the law's provisions that go into effect in June and September of 2010 and are likely to have the greatest impact on a person with CF. Nothing in this article is meant to be a guarantee of specific coverage for anyone with CF. The summary is based on a reading of the law and is based on information available in April 2010. The summary is also based on limited guidance issued by the Department of Health and Human Services, which is drafting the guidance that will implement the law. The mechanics of how certain sections of the law will be implemented has not yet been decided.

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CFRI NEWS**2010 Summer Issue**

CFRI News is published and distributed free of charge to friends of CFRI. Send address corrections and other correspondence to: CFRI: 2672 Bayshore Parkway, Suite 520 Mountain View, CA 94043
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Notes from our Executive Director

This issue of CFRI News chronicles a number of new and exciting turning points for the cystic fibrosis community.

In collaboration with Stanford Hospital, we are completing our inaugural year of the CF Discovery Series™. Generous sponsorship from Genentech, Inc. and A-Med Health Care allowed us to offer this series of informative presentations free of charge to attendees. The story (page 8) documents our pilot year of this program created to further support the CF community. Please check for upcoming programs: www.CFRI.org.

In our cover articles Beth Sufian, an attorney with cystic fibrosis, describes the implications of the new National Health Care Plan and how it affects those with CF, and Siri Vaeth-Dunn describes the significance of CF genotyping. Bridget Barnes shares information about a new FDA approved drug for CF, Gilead Science's Cayston (page 3).

Further information on Cayston and Eurand's ZenPep will be presented at our annual CF National Family Education Conference which will be held from July 30 – August 1. This year's theme is "Quest for Better Health: Whatever It Takes," and we have an exciting slate of CF experts (page 4). For those interested in the latest research, we will also have a presentation by CFRI post-doctoral fellows.

Our Teen & Adult Day Retreat, "Must See TV: CF in Hi Def" (page 13), follows from August 3 – 9, and features high connectivity, value and fun with other CF friends who understand what it's like to live with cystic fibrosis. Located ten minutes from Stanford Hospital, Vallombrosa provides a beautiful



setting, good food and the space to relax together. Scholarships are available. Register on-line at www.CFRI.org.

The 26th annual CFRI Golf Tournament is held on August 2nd at Cinnabar Hills, one of the San Francisco Bay Area's finest golf courses, which is routinely ranked among the top 10 golf courses in Northern California.

Register directly at <http://golfsignup.com/s/CFRIgolftournament.aspx> (page 11).

Our wholehearted thanks to the many sponsors who enable us to continue hosting these events, and to all who contribute to our programs and our research. If you have already responded to our Mothers' Day Tea invitations, a sincere thank you; if you'd like to learn more, it's not too late (page 12). Last year CFRI increased research funding by more than 40% thanks to your continued support.

We would love to see old friends and meet new ones at any of our events. Come share in the joy of discovery and the power of learning this summer.

Warmly,

Carroll Jenkins

Executive Director

(650) 404-9977 • cjenkins@CFRI.org

CFRI Welcomes Two New Board Members

CFRI is pleased to announce the addition of two new Members to its Board of Directors, **Ann Jones** and **Kristin Shelton**, who were recently approved by CFRI's voting membership.

Ann Jones serves as the Chief Business Officer for the San Jose Unified School District and has been a long-time supporter of CFRI. Kristin Shelton is a Respiratory Therapist at Lucile Packard Children's Hospital, and has worked in the CF center for more than twenty years. CFRI is grateful to have the expertise of these extremely qualified individuals.

Of Note –

July 30 – August 1, 2010 CFRI 23rd National CF Family Education Conference

Sofitel, San Francisco Bay
Registration and hotel discounts:
www.CFRI.org

Monday, August 2, 2010 CFRI Golf Tournament

Cinnabar Hills Golf Course, San Jose, CA

August 3-9, 2010 CFRI Teen & Adult Day Retreat Vallombrosa Center, Menlo Park, CA

FDA Approves First New Inhaled CF Drug in Ten Years

By Bridget Barnes

The bacteria *Pseudomonas aeruginosa* is up against a brand new weapon in the arsenal that combats life-threatening infections associated with cystic fibrosis. Formerly known as AZLI (Aztreonam Lysine for Inhalation), Cayston is the first new inhaled drug approved by the U.S. Food and Drug Administration in over a decade for the treatment of cystic fibrosis. The new antibiotic contains the active ingredient aztreonam, a monobactam antibacterial which improves respiratory function in people with CF who have *Pseudomonas aeruginosa*, and provides a much needed alternative for CF patients who battle recurrent lung infections and often develop resistance to other existing antibiotics.

Developed by Gilead Sciences, Inc., with significant support from the Cystic Fibrosis Foundation (CFF), Cayston is the first CF drug to advance from beginning to end through CFF's Therapeutic Pipeline, which is designed to speed up the development of new CF therapies. Cayston is supplied as a single-use vial for both adults and children ages seven and older and is inhaled using an Altera nebulizer – a portable nebulizer approved only for Cayston using the eFlow technology – which allows patients to take the medication in less than five minutes. With a treatment regimen that averages three to four hours a day, this reduced delivery time eases the burden on patients.

Dave Martin, a 43 year old with cystic fibrosis who participated in the clinical trial for eight to ten months finds the inhalation of Cayston to be “like a breath of fresh air,” due to the reduced treatment time. “Although I haven't experienced noticeable lung function improvements, it is an added bonus that Cayston is administered via the Altera which speeds up treatments.” Martin uses Cayston on alternate months when he is not using TOBI.

Dr. Christopher Brown, Director of the California Pacific Medical Center (CPMC) Adult CF Program and Principal Investigator for the Cayston study at CPMC, provided the following comment on his

findings: “Since fall 2008, several of our patients have been using AZLI through the Gilead Expanded Access Program. I've been pleased with the patients' response to the drug. It is well tolerated and seems to work well to suppress and delay pulmonary exacerbations. Although the three times a day dosing seems onerous, our patients have not had too much trouble keeping to the schedule.”

FDA approval of Cayston was based on a randomized, double-blind, placebo-controlled, multi-center trial involving 164 patients. The patients received either Cayston or a placebo administered by inhalation three times a day for 28 days. Statistically significant improvements were seen in both adult and pediatric patients, but were smaller in adult patients. The treatment difference at Day 28 between Cayston-treated and placebo-treated patients for percent change in FEV1 was statistically significant at 10%. Two weeks after completion of drug treatment, the difference in FEV1 between Cayston and placebo groups had decreased to 6%.

DJ Kaley, RN, and Pulmonary Nurse Case Manager at Bay Area Pediatric Pulmonary, Children's Hospital and Research Center in Oakland, who has worked with CF patients for 34 years believes, “Cayston is not a drug to be used lightly just because it is the latest on the market. It is very expensive and obtaining prior authorization requires a great deal of medical justification.” Her prior experience with AZLI was with patients who had *Burkholderia cepacia* and as Kaley noted, “It did help; we used the old injectable form and delivered it off-label, which is what prompted the studies for the current form.”

For the treatment of *Pseudomonas aeruginosa*, Kaley thinks, “Cayston is a useful tool in our arsenal, along with the well-established drug TOBI. Cayston offers



another approved and on-label drug to reduce the infectious load during the off-TOBI month.”

Before taking Cayston, it is recommended that patients do their other inhaled therapies first, such as bronchodilators and mucolytics. As always, if you have questions about Cayston or how to take it, talk to your CF healthcare team.

Cayston and the Altera nebulizer can only be obtained from select pharmacies, including Cystic Fibrosis Services, IV Solutions, Foundation Care, and Pharmaceutical Specialties. If you have insurance problems or cannot afford Cayston, Gilead has established the Cayston Access Program which is designed to minimize barriers and increase access to Cayston for uninsured, privately insured and government-insured people with cystic fibrosis. This program assists CF patients and members of their health care team with insurance verification, referral to participating specialty pharmacies, co-pay assistance and claims support. For more information, call 1-877-722-9786, or visit www.Cayston.com. For most patients with private insurance, the prescription cost will be limited to a co-pay of \$25, thanks to Gilead's support.

More information about Cayston will be presented at CFRI's annual National Cystic Fibrosis Family Education Conference, *Quest For Better Health: Whatever It Takes*, which runs July 30 through August 1, 2010. Dr. Noreen Henig, Director of Medical Affairs at Gilead Sciences, Inc. will give the presentation on Cayston as part of a talk entitled, *Success of the Quest: Newest FDA Approved Drugs*. A question and answer period will follow.

*Online Registration Now Available
at www.CFRI.org*



**23rd National Cystic Fibrosis
Family Education Conference**

Quest for Better Health: Whatever it Takes

July 30 - August 1, 2010

**Sofitel San Francisco Bay
Redwood City, CA**



"UK Gene Therapy Update" Eric W. Alton, M.D. (UK)

"Preventing CF Lung Damage" Christopher H. Goss, M.D. (WA)

"Making Wise Drug Choices" Robert J. Kuhn, Pharm.D. (KY)

"Treatments for Posture and Pain" Mary Massery, P.T. (IL)

"Choosing CF as a Doctor and a Parent" Mark R. Weatherly, M.D. (FL)

"Strengthening Couples in CF Families" Damien Wilson, LCSW (WI)

"Success of the Quest: Newest FDA Approved Drugs" Noreen Henig, M.D. (CA)



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Scholarships, CEUs, Early Bird Special

The Power of Community: CFRI's National CF Family Education Conference Offers It All

By Francine Bion and Siri Vaeth-Dunn

In 1988, a small group of concerned families staged the first CFRI conference. Ann Robinson, CFRI's first Executive Director remembers, "It was just a half-day event. Everyone brought a bag lunch and we made our own coffee. We've come a long way!" As the 23rd National Cystic Fibrosis Family Education Conference approaches, it is evident how successfully it has evolved over the years to become a vital three-day event where over 200 attendees share support with their peers and gain knowledge from internationally renowned CF experts.

Organizing the annual conference requires a veritable army of dedicated volunteers, financial sponsors, and hardworking staff. At the center of this activity is CFRI's Conference Committee, chaired by Isabel Stenzel Byrnes. Other members include: Alisa Evans, Ann Robinson, Barbara Curry, Francine Bion, Patty Acedo-Holmquist and Terry Nelson. Carroll Jenkins, David Soohoo and Mary Convento of the CFRI staff are key members of the committee. The United States Adult CF Association (USACFA) also participates, and is represented by Cynthia Dunafon, Laura Tillman and Richard DeNagel.

Planning this important event is a year-round activity. Immediately after the conclusion of the conference, evaluations are reviewed, a new theme is selected and the planning begins. Attendee evaluations have a significant impact upon both informational content and logistical issues. For example, attendees often make suggestions for topics to explore at the following year's conference. These can assist the committee in targeting select speakers.

A challenging, but crucial task for the committee is the development of the conference

theme. "Living a Medical Miracle," and "In It to Win It" are examples of themes from the past which were woven throughout the event. Terry Nelson utilizes her artistry and imagination to develop engaging hospitality rooms based on the annual theme. The theme guides committee members as they identify medical professionals who offer their expertise and knowledge in an engaging way that is accessible to the many lay people who attend.

Committee members carefully plan for a balanced representation of experts, including clinicians, researchers, psychologists, social workers, nurses, pharmacists, lawyers, insurance agents, nutritionists, and educators. Presenters are recruited from around the globe.



Mark Dovey, MD, gives his CF clinical research update presentation at last year's conference.

The blend of camaraderie and information is key to the conference's success. As one attendee wrote in an evaluation, "Great mix of information and support for patients and families... how wonderful to see this combination of head and heart!" In addition to hearing from CF specialists about cutting-edge research and other clinical issues, people with CF, as well as their loved ones, come together and share support and encouragement. The support sessions are run by professional psychologists and social workers and are extremely popular with attendees, many of whom live in locations where they feel isolated from the CF community.

CFRI is a leader in providing events in which cross infection is addressed and carefully managed. All attendees with CF must present a recent sputum culture and be cleared by their CF Center physician. Every effort is made to minimize cross infection risks. Strict hygiene protocols are reviewed daily and allow conference attendees to come together while providing peace of mind. In addition, a nurse familiar with CF is always in attendance and Stanford Hospital's CF Center is nearby.

The support of conference sponsors is critical to the event's success. Representatives from CF-related companies have an opportunity to meet with the people they serve, while their financial support allows CFRI to offer the event at an accessible rate.

The Conference Committee is committed to disseminating the knowledge that is shared at the annual event. Most sessions of the conference are recorded, and DVDs of these presentations are available for the cost of duplication and mailing. It is hoped that in the future, technology will allow

remote connections for those who are unable to physically attend.

CFRI's National Cystic Fibrosis Family Education Conference is a valuable resource for the CF community. Thanks to the efforts of CFRI staff, volunteers and sponsors, people from around the country can receive the information and support they need to cope with the challenges of cystic fibrosis.

As one attendee wrote after last year's conference, "I have to say this was the best year yet. The speakers were educational, entertaining, and inspiring. I made new friends and connected with old ones. I'll be back next year..."

OUR FOUNDERS: Chuck and Jody Nelson—Encouraging Our Progress

By Ann Robinson and Darrell Batchelder

Chuck and Jody Nelson became founding members of CFRI in 1975 at the time of the organization's incorporation as a nonprofit. Chuck says, "We helped found CFRI because we wondered what the point was of sending all our money back east when we had researchers who could do basic research locally and be more responsive to our concerns." Chuck and Jody are amazed at the research progress over the years. Chuck says, "We thought discovering the gene was key, but now it's been over twenty years and while there is no cure yet, we've seen lots of progress. Newborn screening is a big improvement over the unreliable testing of the early days because babies can be treated more aggressively to get a better start."

Two of Chuck and Jody's three children had cystic fibrosis and both have a story

regarding testing. Kim, the older child, was born in 1964 and had an early false negative test. Her brother Scott was born in 1969 and was found to have CF a year later. After Scott's diagnosis, Kim was re-tested and diagnosed. From the beginning, Chuck and Jody were clear about the seriousness of Kim and Scott's disease. Chuck and Jody continued, "Enjoy your children while you've got them. Answer their questions honestly and be 'cautiously optimistic' in answering."

Jody shares, "We tried our best to treat them as everyday normal kids. We believed in letting our children be children. We never said, 'No, you're not going to make the team,'" says Jody. "Kim was a tough-minded kid who made up her mind and then did what she wanted. In his teen years, Scott had to be reminded about his meds, but Kim was 'Johnny on the spot' in doing hers. She was a strong girl. She was on the debate team at San Jose State and



The Nelson Family, Scott, Chuck and Tammie (top), Jody and Kim

traveled a lot when the nebulizers were bigger and heavier to carry and the enzymes were larger than Tylenol capsules. She had to take a dozen or more enzymes at a time as they were not as concentrated as they are today." Scott was active during his teen years and loved to ski. But he didn't have the energy to ski more than half a day. Before he passed away at 21, he told his dad, "Thanks for letting me

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The Heart of a Volunteer: Elyse Goldberg

By Bridget Barnes

Elyse Goldberg's primary reason for chairing the first CFRI Educational Conference in 1988 bears an uncanny metaphorical resemblance to the quilt she recently made which pays tribute to CFRI's Mothers' Day Tea senders—she wanted to patch together the CF population through education, encouragement and kinship. At that time, "The CF population was very disconnected; people came from far away to gain knowledge, create friendships and get emotional support for themselves and their family members. I really enjoyed the support group aspect of the conference."

Goldberg began volunteering for CFRI when the Palo Alto office first opened its doors in 1985 with some of the organization's first members, including Ann and Rob Robinson, Robin and Doug Modlin, Valerie Baldwin and Marlene and Jeff Wine. Ann Robinson's "very gracious



Elyse Goldberg

way of asking" was what led her to chair the very first conference committee. She recalls, "Our first conference was similar to the current format with lectures, panel discussions about topical issues, and support groups. As it continued to grow, people attended from as far away as Europe,

as did founding members of USACFA." There was one element however that was very different in those days – there were no cross-infection rules. "You could have meals together. There were no restrictions and no Purell."

When asked if she still attends the conference, Goldberg explains, "A culture changed my life. I wish with all my heart that I could go but I can't because of cross

infection." Having two small children redirected her interests and her days "got pretty full combining hours of treatment to balance hours of Play Dough, water fights and baking cookies."

Even though Goldberg is unable to attend the annual conference, her deep devotion to CFRI is felt everywhere. Her current act of kindness is a quilt she conceived of and assembled honoring fellow Mothers' Day Tea senders, which now hangs on the wall of the CFRI office. "Mary (Convento, CFRI staff) really helped with the logistics and getting the squares to me from the quilters so I could assemble them. I didn't anticipate the flood of emotions I'd feel upon seeing the names of so many people I knew and spent time with in the hospital," she says. "It was like a 'reunion of us' in my quilting room. I remembered their lives and laughed at some of the hospital jokes. The quilt is for the Tea senders, and honors and remembers the people I know and knew with CF, and their

(Continued on page 15)

“What’s New?” Testing for CFRD

By Laura Tillman,
President, United States Adult
Cystic Fibrosis Association (USACFA)

Cystic Fibrosis Related Diabetes (CFRD) is caused primarily by damage to the pancreas which results in a reduction in the amount of insulin that the pancreas supplies to the bloodstream. This is likely due to scarring of the pancreas because of mucus. Another cause of CFRD is insulin resistance, which means that the cells in the body do not use insulin correctly so more insulin is needed to convert food into fuel and keep blood sugars in the normal range. Higher than normal cortisol levels can also cause insulin resistance. The hormone cortisol is a steroid made in the adrenal glands.

While CFRD shares features of Type 1 and Type 2 diabetes, it is a unique and distinct form of diabetes. There are two types of tests for CFRD: an Oral Glucose Tolerance Test (OGTT), which measures blood sugar levels two hours after drinking a ‘sugar’ solution; and a Fasting Blood Glucose (FBG) test where individuals fast before taking the test. There are different schools of thought regarding testing, as can be seen in the following summaries:

Cystic Fibrosis-Related Diabetes in Childhood,
Stephen M.P. O’Riordan, (et. al.) Hormone Research in Pediatrics, 2010: 73:15-24.

CFRD is usually asymptomatic and can remain undetected for up to four years prior to diagnosis. Patients who develop overt symptoms of hyperglycemia on presentation have a relatively greater decline in pulmonary function and weight loss as compared with those identified on monitoring. Therefore, it is important to identify patients by monitoring before the onset of symptoms. The following methods of CFRD monitoring have been considered: hemoglobin A1c (HbA1c), random or fasting glucose concentrations, oral glucose tolerance test (OGTT) and Continuous Glucose Monitoring (CGM). <http://tinyurl.com/y5b7bcg>

Routine Screening for Cystic Fibrosis-Related Diabetes. Daniel Peckham. Journal of the Royal Society of Medicine 2009: 102: S36–S39.

CFRI Attends Inaugural CF Learning Center Conference

Executive Director, Carroll Jenkins, represented CFRI last March at the Cystic Fibrosis Learning Center (CFLC) Continuum of Care Conference in Jersey City, New Jersey. Nearly 200 cystic fibrosis (CF) healthcare professionals, family members, and health-



Carroll Jenkins and Nick Lombardi at the CFLC conference in New Jersey.

care industry personnel participated in two-and-a-half days of education and networking within the CF community.

Two concurrent educational tracks were offered for both healthcare professionals and CF family members. Sessions targeted pressing issues facing all members of the CF healthcare team — pulmonologists, nurses, nurse practitioners, registered dietitians, respiratory therapists, and social workers — as well as family and friends involved in CF care on the home front.

Despite overwhelming evidence for screening and the presence of national guidelines, clinical practice varies significantly across the UK. This variation may be a reflection of the complexity and variability of glucose metabolism in CF and the absence of a simple and specific screening tool. Appropriate resources need to be invested into screening patients with CF for CFRD so the adverse impact of late diagnosis on health status can be negated. Waiting for patients to present with diabetic symptoms in the absence of a screening tool is no longer an acceptable practice. <http://tinyurl.com/yybobd2>

New Criteria for Impaired Fasting Glucose and Screening for Diabetes in Cystic Fibrosis.

C. Mueller-Brandes, (et. al.) European Respiratory Journal 2005: 25:715-717.

Conference planners ensured that attendees were well taken care of and had time to interact. Many were interested to learn about the support services CFRI provides, and were glad to hear about our upcoming National Family Education Conference.

Nick Lombardi, Co-Founder of the Cystic Fibrosis Awareness Foundation, created this first class event, which fostered new learning and networking for parents and providers. Lombardi is Vice President of Grant Development for the North American Center for Continuing Medical Education (NACCME), a sponsor of the event.

The second CFLC Continuum of Care Conference will take place in April 2011. We look forward to joining that event! For further information, visit www.CFLearningCenter.com.



Lisa Yourman (right), a CF parent, patient advocate, and committee member of “Heroes of Hope,” visits with parents from the CF community.

If the diagnostic aim is the early identification of patients with CFRD Mellitus and immediate treatment for those with a positive diagnosis, the American Diabetes Association approach of using Impaired Fasting Glucose as an indication for performing selective OGTT’s is unsuitable in the CF population, and cannot replace an annual OGTT as a screening test for CFRD. <http://tinyurl.com/y5mzjeg>

Managing Cystic Fibrosis-Related Diabetes (CFRD).

An Instruction Guide for Patients and Families. Carol Brunzell, R.D., C.D.E., L.D., Dana S. Hardin, M.D., (et. al.). Copyright 2008 Cystic Fibrosis Foundation.

(Continued on page 15)

CF Discovery Series™

By Carroll Jenkins

The “CF Discovery Series™” is an informative and engaging program designed to educate and uplift those with cystic fibrosis. Through interactive presentations with experts in the field, those living with CF gain information in a setting which encourages camaraderie and community.

Nurse practitioner Camille Washowich, MSN, ACNP, at the Stanford Adult CF Clinic, and Carroll Jenkins, CFRI Executive Director, have developed a variety of presentations which focus on living longer and healthier lives with cystic fibrosis. As more adults with CF are enjoying family and careers, requiring them to cope with stresses rarely imagined by previous generations, balancing the multiple tasks of everyday adult life while managing a complicated disease can be overwhelming.

In addition to the physical challenges of CF, many patients face financial, emotional and logistical concerns. Left unresolved, these issues can lead to additional stress, which in turn may affect how well people with CF care for themselves.

Topics of discussion for 2009 – 2010 have included: compliance, the healing power of humor, support for caregivers, stress management, depression, nutrition, exercise, alternative/complementary medicine, reproductive issues for those with cystic fibrosis, lung transplantation, motivation, and spirituality. Volunteer speakers are experts in their field and include Stanford staff and faculty, CF caregivers and other professionals in the community.

For example, Dr. Paul Turek, Director of the Turek Clinic and Dr. Lynn Westphal, Director of Women’s Health at Stanford discussed reproductive issues for people with CF. Dr. David Weill, Director of CF & Lung Transplant at Stanford and Mary Martel, NP discussed the many issues related to lung transplantation. Dr. John Mark, Pediatric Pulmonologist at Lucile Packard Children’s Hospital at Stanford (LPCH), discussed alternative therapies for reaching the highest quality of life. Julie Matel, MS, RD, CDE, Pediatric Nutritionist at LPCH shared up-to-date information on nutrition for the CF community.

Other presenters explored issues that impact the well-being of those with CF. Dr. Julie Desch, exercise coach and owner of New Day Wellness, encouraged people



Dr. John D. Mark, Pediatric Pulmonologist, Lucile Packard Children’s Hospital at Stanford.



Dr. David Weill, Director of CF & Lung Transplant at Stanford.



David R. Cartnal, F.A.I.A.



Cynthia McDonald, Ph.D., MdHT, Medical Hypnotherapist of Transformative Living, LLC, pictured with Eric Marten and Cindy Art, attendees at the Discovery Series.

A Rewarding Partnership!

to establish a fun and rewarding exercise program. Cynthia McDonald, Ph.D., MdHT, a Medical Hypnotherapist of Transformative Living, LLC spoke about tapping into the transpersonal to improve well-being. Dan Chan, the “Magic Man,” performed a show which reflected the “magic” of compliance in enhancing the quality of life. David R. Carnal, F.A.I.A., who describes himself as a “CF-Patient who refused to take ‘NO’ for an answer,” inspired attendees with his view of living life fully at any age with CF.

The “Cystic Fibrosis Discovery Series” name was inspired by an adult with CF who commented, “It is much more meaningful to discover for one’s self than hearing a lecture. The best work can be done by people with CF helping each other.” The program is working to create an interactive CF community reminiscent of years past, yet which incorporates today’s infection control protocols.

To create a safe environment, CFRI’s cross-infection guidelines for patients with CF are followed: hygiene packets which include hand gels, masks and tissues are provided for each attendee; adults with CF are reminded to sit at a distance from one another; and a volunteer wears gloves to serve refreshments. As with all CFRI events, adults with CF who have ever had a confirmed positive sputum culture for *Burkholderia cepacia* (*B. cepacia*), or who have cultured Methicillin-resistant Staphylococcus aureus (MRSA) within the past two years, or who are currently culturing pathogenic bacteria resistant to all antibiotics may not attend the Discovery Series.

Organizers are committed to making the information available to all, including those unable to attend. Thanks to videographer Scott Wakefield, many of these sessions have been filmed and will soon be available on DVD, as well as through handouts and PowerPoint presentations.

The CF Discovery Series is open to adults with CF, families and friends. It is held at the Crowne Plaza Cabana in Palo Alto. Further information about our coming 2010-2011 programs will be posted on the CFRI website: www.CFRI.org.

Many thanks to the generous support from Genentech, Inc. and A-Med Health Care.

The Discovery Series is free of charge to attendees.



Dr. Paul Turek (far left) Director of the Turek Clinic and Dr. Lynn Westphal (far right) Director of Women’s Health at Stanford.



Julie Matel, MS, RD, CDE, Pediatric Nutritionist at Stanford.



Dan Chan the Magic Man clowns with Camille Washowich. Dan spoke about the “magic” of compliance for better health with CF.



Carroll Jenkins, CFRI, with Dr. Julie Desch.



Health Care Reform (continued from page 1)**EFFECTIVE JUNE 2010:****1. Temporary National High Risk Pool:**

In June 2010, a Temporary National High Risk Pool (“Risk Pool”) will begin. The Risk Pool will provide coverage to adults who have been uninsured for at least six months as a result of a pre-existing condition and will exist until 2014. In 2014, insurance companies will no longer be able to deny coverage to adults with pre-existing conditions. The new Risk Pool should have premiums that follow standard insurance rates for the average person applying for health insurance. No premium price structure is available at this time. This applies to all new employer plans, new plans in the individual market, and existing employer plans.

EFFECTIVE SEPTEMBER, 2010:**1. Coverage for Dependents Under 26:**

Beginning in September 2010, children can stay on a parent or guardian’s health insurance plan until the age of 26. If a child has reached a limiting age on a parent’s policy but has not yet reached the age of 26, the child can return to the parent’s policy in September 2010 when this section of the law becomes effective. For example, Isabella turned 18 in April 2010. Isabella had reached the limiting age on her parent’s policy and so lost coverage under her parent’s plan. Isabella will be able to re-enroll in her parent’s policy in September 2010. There is no requirement that a child under the age of 26 be enrolled as a full-time student. Some individual insurance companies have decided to implement this section of the law earlier. Parents with children who are under 26 and are in need of insurance coverage should contact their insurance company to see if the child can re-enroll now.

Children under 26 who work for an employer who provides health insurance coverage will NOT be able to stay on their parent or guardian’s health insurance plan once they reach the limiting age set in their parent’s policy. However, in 2014, even if a child’s employer offers coverage the child can elect to stay on the parent’s policy until the child turns 26 years of age.

2. Individual Coverage for Children:

Beginning in September 2010, pre-existing condition exclusions for children must be eliminated in all health insurance plans. This includes individual health insurance policies. This section of the law should mean that a parent who has a child with CF could purchase an individual policy for their child. Details regarding this section of the law should be available soon.

3. Lifetime Caps: All new and existing health insurance plans must eliminate lifetime caps in September 2010.

4. Annual Caps: Prior to 2014, annual caps on coverage will be restricted as allowed by the Department of Health and Human Services. This means it is likely an insurance company will have to follow rules set by the government regarding their ability to impose annual caps on coverage. Starting in 2104, annual caps on coverage will not be allowed.

5. Rescission of Policy: Effective in September 2010, a health insurance company cannot cancel coverage due to higher use of benefits or diagnosis of a new medical condition. The policy can be cancelled if the policyholder committed fraud in obtaining the policy or while enrolled.

6. Medicare Recipients: Adults with CF who are receiving Social Security Disability Insurance and Medicare will see new benefits thanks to the law. In 2010, Medicare recipients will receive a \$250 rebate if the individual reaches the “donut hole” in Medicare Part D. In 2011, the donut hole will be reduced by 50%. By 2020, the donut hole will be eliminated. For individuals with CF who are on Medicare this section of the law will reduce the amount of money the adult has to pay for prescription medication.

You can contact the CF Legal Information Hotline at 1-800-622-0385 with any questions about the Act. Also, you can follow the issuance of guidance on the government website: <<http://www.healthcarereform.com.>>

Genotyping (continued from page one)

any protein production to the presence of almost normal levels of protein in the cell surface but with decreased function. This for the most part translates to some aspects of the clinical condition.”

Cystic fibrosis has historically been seen as a disease largely impacting those of European descent. The expanded implementation of newborn screening programs has provided an opportunity to better measure the range of mutations in the general population, as well as their prevalence in varying ethnic groups. Data from California’s newborn screening program, initiated in 2007, is especially interesting based on the ethnic diversity of the state. In its first year of screening, 561,857 newborns were screened for the 38 most common CFTR mutations. Seventy-eight babies were diagnosed with CF, while 25 had positive CF blood tests but normal sweat chloride results, with a distribution of 48% Caucasian, 38% Hispanic, 2% African American, and 12% bi-racial.

At Lucile Packard Children’s Hospital at Stanford, nearly half the babies found to have CF through the newborn screening program are Hispanic, and within this group clinicians have observed newborns with lung disease, but with pancreatic sufficiency. For these infants, the correlation between healthy weight gain and good lung function does not always hold true, as studies show that Hispanics with CF often have more significant health issues than their Caucasian peers. Unfortunately, the identification of one’s mutation is only a piece of the puzzle. Adds Dr. Milla, “For the pancreatic problems there is a good correlation between the type of mutation and the disease severity. However, for the pulmonary and infectious problems this is not as clear-cut, except for the most severe manifestations. This has spurred a tremendous interest in identifying other factors that might be involved in the clinical manifestations of CF.”

Dr. Milla is currently overseeing at Stanford the HOLA - CF (Health Of Latin Americans with Cystic Fibrosis) study led by Dr. Kim Watts from Northwestern University, to determine whether modifier genes present in the Hispanic CF population may help to explain the difference in

(Continued on page 14)

Quilted Memories

By Robin Modlin

One afternoon last September, Elyse Goldberg visited the CFRI office to participate in the Healing Flags Project for the Japan trip described in the last issue of *CFRI News*. Elyse heard that CFRI was seeking a way to honor the Mothers' Day Tea senders through a work of art. The idea of a quilt was discussed and then - like magic - it became her project. Elyse did not anticipate volunteering for such a large and involved enterprise, but she is very glad she did. What was to be a simple and symbolic project grew into a very meaningful and artful journey of reminiscence and hope.

Elyse has been an involved member of the CFRI community for 25 years. After moving to the San Francisco Bay Area from Southern California, she became a patient at Lucile Packard Children's Hospital at Stanford. Her warmth and contagious laugh have touched many and sparked friendships with numerous CF patients and their families. Elyse's long history with the CF community made the quilt project especially meaningful for her.

The CFRI community was asked to create a quilt square, either in honor or in memory of someone with CF. This quilt features a piano key border surrounding a variety of rose fabric prints, recalling a rose garden and displaying the names of numerous CF patients. As the squares arrived to be sewn together, the names Elyse

knew so well filled her with long-held memories. Names of original founders of CFRI, as well as the names of newer families with young children were sewn into a patchwork of heartfelt love and hope, and symbolize the fight to conquer cystic fibrosis.



Each of the twenty-four patches on the Rose Garden Quilt was created to honor a loved one with CF.

This process became very emotional as she experienced the power of a community art project. As she touched the squares she remembered the faces of her peers with CF, and the times they had shared together. In many ways Elyse felt that this quilt was similar to the AIDS quilt. When a community of strong, caring people comes together with a common purpose to save the lives of loved ones, a special bond is made. All these feelings are embodied in the quilt. It was especially moving for Elyse, who knows so many who battle daily

with the disease, and remembers so many who have not survived. The heartbreak and the hope are the fabric of this special project.

The quilt serves as a tribute to the Mothers' Day Tea volunteers and families who faithfully raise money to fund CFRI's scientific research and educational support. According to Elyse, "What was most remarkable about being involved in the quilt project was what a small family we are and the deep connection we feel."

The relationships we have in this community both far and wide are deep and unique. When those who live with CF get together there is an unspoken understanding. To those with CF honored in the quilt whom Elyse has not met, she says, "I don't know you,

but I love you." The bond gained through the CF experience, is powerful and a gift we receive from each other.

Though the quilt will be permanently housed at the CFRI office, it is hoped it will be exhibited in community locations to honor our volunteers and raise CF awareness. CFRI is very grateful to Elyse for organizing and completing this extraordinary gift to our community. If you're near our office, please feel free to drop by and view this quilted memory.

CFRI Golf

The 26th Annual CFRI Golf Tournament will be held on Monday, August 2, 2010. This exciting event is held annually at Cinnabar Hills Golf Club in San Jose, a club consistently rated as one of the best public venues in San Jose by local golfers.

It's not all about pars and bogies, however. There are tee prizes, wine and cheese tasting, silent and live auctions including fantastic sports memorabilia, as well as a celebration banquet. Winners also get trophies and bragging rights until next year. Most importantly,

the event raises critical funds to support CF research and services.

Scott Hoyt, CFRI Board Treasurer and Cinnabar Hills General Manager, has provided a new web site: <http://golfsignup.com/s/CFRIgolftournament.aspx>. You may also contact him at (408) 323-7803 or SHoyt@CinnabarHills.com.

Mothers' Day Teapot Still Brewing

By Bridget Barnes

Although the bright summer sun has replaced the cool days of spring, it is still not too late to savor the satisfaction of participating in this year's Mothers' Day Tea. The warm spirit of the Tea continues to "brew" at CFRI. Taking the time to consider a loved one affected by CF is a fulfilling thing to do any time of the year, as is making a donation in their honor.

Our goal is to raise \$254,000 to support first-rate research and programs instrumental in improving and expanding the lives of people with CF. Your donations, which mean so much in light of the current economic climate, continue to be crucial in funding CFRI's New Horizons Research Program, as well as educational programs such as the annual National CF Education Conference and Teen/Adult Day Retreat, and outreach materials including *CF in the Classroom* (also in Spanish), the *CF Website Guide*, and *CFRI News*.



Our Mothers' Day Tea Kick-off celebration was a reunion for many Tea Senders. Pictured at front table (clockwise from left) are Sally Kusalo, Pat Flynn, Barbara Bonar, Pamela Nett and Ann Robinson.

We received our first donation of 2010 in early March. Since then, tea senders have responded with over 1,500 donations, and

more arriving daily. Margaret and Larry Byrnes won the elegant white "Emma" teapot generously donated by longtime CFRI volunteer Pat Flynn.

If you want to become a Tea Sender please call our office at (650) 404-9975, or email: CFRI@cfri.org, or order online at <http://www.cfri.org/formMDT2010.shtml>. We will be delighted to provide you with everything you need and in turn you will have the pleasure of participating in CFRI's biggest fundraising event, which helps support families, children and adults living with cystic fibrosis.



Our Mothers' Day Tea Committee includes (left to right) Pat Flynn, grandmother of Devin with CF; Ann Robinson, CFRI's first Executive Director and mother of Carl with CF; and Barbara Curry, grandmother of Cameron with CF.

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

Your Name (please PRINT)

(Area Code) Telephone Number

PO Box/Street Address

City/State/Zip

Email Address

Relationship to CF

(Complete and mail to CFRI)



Must See TV: CF in Hi-Def!



Meet some great friends.



Learn more about CF self-care.



Feel that you're not alone.



Experience 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 time to hang out and get to know others.

Cost: \$85 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. Some scholarships are available.

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.

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

We'd love to see you!

Register online at www.CFRI.org or contact CFRI for an application:

CFRITM Cystic Fibrosis Research, Inc.
2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043
(650) 404-9975 Fax: (650) 404-9981 cfri@cfri.org www.cfri.org

In Honor of

(Contributions listed were received from
March 1, 2010 to April 30, 2010)

Claire Alexander
Gianna Rose Altano
Sadie Anderson
Rebecca Atkins Swank
Haleigh Baker
Lucy Barnes
Jamie Barry
Joe Batchelder
Makinnon and Marin Baugh
Allison Best
Susan, Darryl, Aidan, Oliver and
Ellis Biggar
Robert Bly
Emily Broshi
Anita Cass
Shaun Collins
Michael and Allison Conway
Barbara Curry
Carolyn Daley
Gordon DeVore
The Detrick Family
Erin Donelson
Tess Dunn
Danny Ellett
Hayden Ellett
Alanah Fink
Jarrod Fischer
Ryan Foster
Dr. Allan Frank
Emily and Jessica Fredrick
Mark E. Gerow
Jenise and Larissa Giuliano
Elyse Goldberg

Deana Goodman
Emily Gorsk
Barbara Greenberg
Liz and Alec Hampton
Dr. Jeanie Hanley
Kerry Miller Harrison
Tanner Harvill
Arieona Haskins
Max and Abbey Heilman
Ben Horton
Clark Huddleston
Elizabeth Hull
Peggy Jones
The Kennedy Family
Emily Kerr
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Franny Kiles
Ed Kinney
Lori Kipp
Philip and Eleanor Kolchin
Kaitlynn Lackey
Kody Lawrence
Joe Laye
Carly Lee
Maeve Leonard
The Lunehan Family
Marisa Maraco
Claire McCabe
Tessa McCarthy
Mikayla McDonald
Carly McReynolds
The Medeiros Family

Michael Medeiros Reuscher
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Kelly Miller Skinner
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Fiona Mischel
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Anna Modlin
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Alex Moore
The Chuck Nelson
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Brian Tacke
Jake's Team
Heidi Tegner
Victoria Threshie
Rhonda Torres
Siri Vaeth-Dunn
Chris Vallee
Will Vogt
Melissa Weiner
Tanner Williams
Nina Wine
Rabbi Jeremiah Wohlberg

**"In Honor of" allows you to list the name
of a living person in whose honor a donation
has been made.**

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

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

Genotyping (continued from page 10)

health outcomes, and ultimately lead to the development of therapies that address these differences.

What is the future of medical interventions targeted for specific mutations? A strategy with great promise is the development of CFTR modulating therapies such as VX-770, VX-809 and Ataluren (formerly known as PTC 124). Each of these compounds works to correct the defective CFTR in targeted mutations (G551D, Delta F508, and "nonsense mutations" respectively). The Cystic Fibrosis Foundation supports this exciting research.

According to Dr. Milla, "There is growing recognition within the medical scientific community of the need to move to an individualized approach to patient care. Most treatments are prescribed based on what we know about the 'average' patient and the clinical experience acquired by treating

large numbers of patients. However, this often ignores the patient's individual characteristics, including biological as well as environmental and other characteristics likely to play an important role in disease progression and treatment responses."

This year the Cystic Fibrosis Genetic Analysis Consortium – which maintains the CFTR database of over 1,700 mutations – is participating in an international initiative that will take information from the mutations database and CF patient registries around the globe and seek to correlate this "to complete advanced and expert-reviewed functional and clinical information on CFTR mutations." The results should better illuminate the link between genotype and disease expression and may significantly expand the current search for more effective, targeted treatments for cystic fibrosis.

How will this impact CF patients? If Stanford is a model of what is to come, then soon everyone will be well versed in their individual genotype. Adds Dr. Milla, "At Stanford we are committed to move into a new era of CF medical care where we will be at the forefront of the development of CF individualized medicine. In collaboration with members of the Stanford scientific community, we plan to make the best use of genomics and other platforms already available. This will involve not only acquiring full knowledge of the individual patient's CF mutations, but also looking at other genetically determined characteristics like drug responses and responses to infection."

The new era of CF care, tailored to the unique genetics of each patient, is underway.

In Memory of

(Contributions listed were received from
March 1, 2010 to April 30, 2010)

“In Memory of” allows you to honor a loved one you have lost, and in whose memory you have made a donation.

We extend our deepest sympathy to these 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.*

Please send the name of your loved one with an address so that we may send an acknowledgement of your donation. Send to: CFRI, 2672 Bayshore Parkway, Suite 520, Mountain View, CA 94043

Carol Carey	Kathy Judge Morse	Jim Schottland
Gena Carslund	Blake Kelley and Parents	Louise Schroeder
James Cassingham	Kitty Kious	Brady Scillingo
Sonya Chartrand	Bridget Klein	Jeremy B. Selvage
Ryan Coelho	Dorothy Koch	Tammy Smerber
Marjorie Collis	Jeff Kreth	Bunny and Stan
Joseph C. Connell	Jane Ellen Kulik	Robert Stewart
Rachel Crocker	Douglas K. Lab	Robert C. Stewart, Jr.
Mathew DeGregory	Dawn Longero	Kitty Stimac
Charlie Delgado	Fred and Alex Maish	Jeffrey Storm
Marty and Beverly Detrick	Lucy Marsh	Dave, Mel and Laurie Stuckert
Neva DeVore	Ed Merrick	Pat Thibault
Rita Dickinson	Dorothy Miller	Ann Marie Thibault
Elaine Dougherty	Jessica Mobley	John E. Trask
Caroline Drinnan	Elizabeth Nash	Marge Trask
Mel Duezabou	Scott and Kim Nelson	Linda Trojak
Boyd and Pam Faulk	Jack Nichols	Jill Tugin
Laura Gale	Michelle Olson	Jennifer Uskoski
Rosalyn and Isaac Goldman	Adam and Naomi Oneto	Cynthia Lynn Vidak-Haley
Diana Goodman	Sean Peterson	Jodi Voller
Douglas Graham	Bonita Predny	Tom Walton
Stephanie Jo Halling	John Quan	Sean Waltrip
Virgil A. Hanson	Catherine Rawlings	Tara Weir
Nellie Hart	Allison Roberts	Valeria J. Werdeman
Beverly Hillman	Randy Ruprecht	Kelly A. Wilson
Mark and Tracy Holmes	Grace Rush	Cynthia Witman
Leslie Hotson	Siobhan Ryan	Lucille Ziesennehenne
“Hutch” Hutchison	Beth Ann Salser	
Sean Hyland	Carolyn Samuel	
Christopher Ireland	Edith Schlotterbeck	
Peter Judge		

Kimberley Adelman	Ken Baxter
Marc, Kim and Carol Adelman	Anne Beltrame
Sonya Lyn Akister	Amy Bienenstock
Rosemary Altano	George Blair
Gay Archibald	Alicia Brogle
Mary Bakula Johnson	Zelda Brust
Kathleen Baldwin	Kyle Butler
	Thelma Cady

What's New (continued from page 7)

The CF Foundation advises that people with CF have a casual blood glucose drawn at least once a year. A casual blood glucose level is one that is drawn without regard to the time of day or when a meal was last eaten. If this level is less than 100 mg/dL (milligrams per deciliter) or 5.6 mmol/L (millimoles per liter), diabetes is not likely. If this level is 200 mg/dL or 11.1 mmol/L or more, CFRD is likely. <http://tinyurl.com/msugd4>

Screening for Cystic Fibrosis Related Diabetes (CFRD)

Using the Oral Glucose Tolerance Test. University of Wisconsin School of Medicine and Public Health, August 7, 2008. Screening for CFRD should occur every other year for people age 10-16 years and yearly for people older than 16 years. This test may be performed as part of a routine clinic visit at a CF Center. <http://tinyurl.com/y39paa5>

Volunteers (continued from page 6)

families.” For more on the quilt project, see “Quilted Memories,” on page 11.

Another of Goldberg’s many talents is knitting and “as a living tribute to my mom who taught me to knit,” she started the H.A.T.S. (Hope, Attitude, Triumph and Strength) project with a network of knitters and has since distributed over 300 hats to Stanford’s Chemotherapy Infusion Center. “I’m so happy being home in my pajamas making things with my hands and not being in a meeting,” Goldberg says gleefully. At 51, with CF, she tries to exercise every day. “When I feel good, I want to get it all in,” she explains.

When asked if she has any favorite CFRI moments she’d like to share Goldberg says, “Carroll Jenkins - we always have such a good time talking on the phone.” As for what has inspired her to volunteer for CFRI all these years, she replies, “a passion for putting it out of business,” and adds she wants a better control for CF.

“I was raised in a very charitable family. I like people, I believe in the cause, and random acts of kindness make me feel good.” CFRI is deeply grateful to Elyse Goldberg for her many random – and not so random – acts of kindness on our behalf.

Founders (continued from page 6)

live my life my way.” Kim had a double-lung transplant when she was 33 and lived an additional seven years.

Chuck and Jody live in San Jose, California and enjoy visiting with their third child, Tammie, a lead performer who has been singing in San Francisco’s Beach Blanket Babylon for 18 years. The Nelsons have been longtime CFRI tea senders and volunteers. Their continued support of the CF community is most appreciated.

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*Special Thanks to: **Genentech, Inc.**, and **Gilead Sciences, Inc.**
For their generous support of CFRI News.*

CFRI's Mission

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

CFRI's Vision

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



Get to know us:

www.CFRI.org 650.404.9975

